

The Dissertation Committee for Derek Sean Falk

Certifies that this is the approved version of the following dissertation:

**Breast and Cervical Cancer Screening in Rural and Border Texas: A Program Evaluation
of Friend to Friend plus Patient Navigation**

Committee:

Catherine Cubbin, Co-Supervisor

Barbara Jones, Co-Supervisor

Jacqueline Angel

Yessenia Castro

Yuri Jang

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of Friend to Friend plus Patient Navigation**

by

Derek Sean Falk

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**Breast and Cervical Cancer Screening in Rural and Border Texas: A Program Evaluation
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by

Derek Sean Falk, PhD

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SUPERVISORS: Catherine Cubbin, Barbara Jones

This dissertation considers an evaluation of the health education and patient navigation (PN) intervention, *Friend to Friend plus Patient Navigation* Program (FTF+PN). In 2010, the Texas A & M AgriLife Extension Service was awarded outreach education funding by the Cancer Prevention Research Institute of Texas (CPRIT) to adapt the evidence-based program, *Friend to Friend* (FTF) in rural and border counties in Texas. FTF consists of “pink parties” intended for an audience of lower income, un-/underinsured women aged 40+ who may be disabled, self-employed, and/or have limited English proficiency (LEP). Increased funding in 2012 supported the addition of four, fulltime equivalent patient navigators to join the team of four, full-time equivalent regional cancer prevention specialists to allow for follow-up and active support for women to obtain the screenings.

FTF+PN seeks to build an effective, sustainable infrastructure and overcome barriers to breast and cervical screening and diagnostic services to increase screening rates for underserved, un-/under-insured, and older women in approximately 60 rural and border counties. The goal is to increase the number of women screened according to American Cancer Society (ACS) guidelines for breast and cervical cancer, thereby increasing the probability any cancers detected would be diagnosed in earlier stages. At the time, ACS guidelines recommended annual mammograms for women aged 40-54 and biannual mammograms for those aged 55+ with average risk of breast cancer. For cervical cancer screenings, recommendations included Pap tests every 3 years for women aged 21-29 and every 5 years for women aged 30-65 with no additional screenings needed for women aged 65+ if their previous results were normal.

The goal of this evaluation is to demonstrate the efficacy of combining PN, a patient-centered healthcare delivery model that utilizes trained lay navigators to integrate a fragmented system of care in order to reduce barriers to timely care for individuals and subsequently reduce disparities for population groups, with a health education intervention adapted for rural and border Texas. Screening outcomes are also evaluated in light of county-level poverty rates and educational attainment to provide more comprehensive statistical models advancing scientific understanding of screening behavior among varying groups of women.

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Chapter 1: Introduction[†]

Problem Statement

Breast and cervical cancer are ranked as the first and fourth leading cancer diagnosis for women in the U.S. with late-stage diagnoses cited as a possible source of increased treatment difficulty and poorer outcomes for women whose cancer is not detected at an earlier, non-metastatic stage.^{1,2} Given the prevalence of these cancers and variation in outcomes for different population sub-groups, public health policy and practice interventions have sought to identify un-/underserved women, including those living in rural areas, and connect them to resources to screen, diagnose, and treat breast and cervical cancers as early as possible.²

Current literature indicate that rural women screen for breast and cervical cancer at lower rates than urban counterparts.³ Rural residents also suffer from later stage breast cancer diagnoses⁴ and higher breast and cervical cancer mortality rates⁵ compared to urban residents. These findings are further complicated by differences in race/ethnicity, scarcity of local healthcare services, a fragmented healthcare system, socioeconomic status (SES), and measures of area social deprivation that may factor into poorer outcomes for women in rural areas of the United States.⁵ Systematic literature reviews have assessed studies focusing on screening access and utilization,³ and stage of diagnosis⁴ for rural women, but none have reviewed interventions aiming to increase screening among rural residents.

[†]A version of this chapter including its subsections was previously published following the dissertation defense. The committee reviewed and accepted this article for inclusion in the dissertation. The material is reprinted with permission from Taylor and Francis Group.

Falk, D. (2018). A mixed methods review of education and patient navigation interventions to increase breast and cervical cancer screening for rural women. *Social Work in Public Health*, 1-14. doi: 10.1080/19371918.2018.1434583

SES status and rural residence also intersect with access to health insurance, which is often related to marital status. Substantial literature documents the processes by which marital disruption leads to poorer health outcomes in light of reduced access to health insurance following a divorce.⁶⁻⁸ Furthermore, low-wage women also have a great deal of variability regarding access to health insurance depending on the composition of their employer, fellow employees, and marriage status due to the influence of these factors on the cost and subsidies provided through current health care legislation.⁹ While marital status is not assessed in this study, this factor adds still another dimension that generates disparate outcomes for rural women, especially in the face of economic restructuring and increased marital instability in rural areas.⁸ As a result, interventions focused on providing access to health services for lower SES rural women bare even more relevance to this study.

State specific legislation reducing publicly funded family planning services has also led to reduced access to care as these locations have served fewer women over time and limited their presence across the state.^{10,11} The loss of these providers, who often served larger roles in women's health care by providing breast and cervical cancer screening, again impacts women of lower SES status and reduces the number of providers in areas already experiencing limited resources. While the reduction in providers over time has not been assessed directly in this study, once again it justifies offering breast and cervical cancer screening services who can no longer rely on the few resources available for them, particularly in areas that demonstrate higher rates of cervical cancer in comparison to other parts of the state and the country.¹²

Patient Navigation

Patient navigation (PN) emerged in the 1990s as a means to address breast cancer disparities by increasing screening among underserved women of color by reducing barriers to

care within a fragmented health care system.¹³ Since then, PN has drifted from its original clinical setting to include interventions across the cancer continuum with demonstrated efficacy in preventative screening uptake.^{14,15} However, its rapid adaptation across the country, including rural areas, has led to debate fostering greater formalization of what defines patient navigation in a professional context and how to measure its effect in health outcomes research.^{16,17} Even more, few studies (n=2) in rural settings have analyzed social work's place in oncology PN as either navigators or serving in some other capacity within a PN intervention.¹⁸ In an attempt to integrate a diverse evidence base into practice standards, the Oncology Nursing Society, Association of Oncology Social Work, and the National Association of Social Workers issued a joint position stating a multidisciplinary team composed of a social worker, nurse, and lay navigator provide for optimal patient outcomes when using PN.¹⁹ This initial review seeks to identify and compare programs aimed at improving mammogram and Papanicolaou (Pap) screening rates for rural women who exhibit poorer screening behavior, later-stage diagnoses, and higher mortality rates than urban women.

Understanding PN and its functions have become even more critical as accreditation standards now require cancer treatment facilities to offer these services, which are defined by the Commission on Cancer as²⁰:

“... specialized assistance for the community, patients, families, and caregivers to assist in overcoming barriers to receiving care and facilitating timely access to clinical services and resources. Navigation processes encompass pre-diagnosis through all phases of the cancer experience.”

However, other authors have noted navigation training and implementation depend greatly on the individual cancer program employing these services.²¹ Furthermore, the accreditation standards

clearly situate PN within an institutional setting despite the need for cancer care services in rural areas lacking facilities to meet these goals. Consequently, PN has been defined more so by the goals of the intervention rather than a consensus of roles and duties for navigators across implementation sites. An assessment of breast cancer PN programs used nine key principles rather than a taxonomy of duties to evaluate PN.²² These principles based on Freeman's work included eliminating barriers to timely care, providing patient-centered care, integrating a fragmented system, navigating across a disconnected system, program cost, the navigator's skill level, predetermined start and endpoints of navigation, the scope of the role, and system coordination. Again, this study found different expressions of PN based on how each program chose to interpret PN within the context of its institution with varying levels of adherence to these principles.

A national survey of patient navigators and their roles found basic navigation (assessment of needs, identification of barriers, problem solving based on needs, explaining PN services) were common across programs and employed lay, trained individuals in addition to medical professionals to perform these functions; however, treatment support and clinical trials/peer support required specialized professionals including social workers and nurses to perform these duties.²³ The authors note three prevailing models of PN where the first involves a community member who negotiates with providers and is often a lay individual, the second involves screening and treatment navigation by social workers or nurses often in a clinical setting, and the third includes a multidisciplinary team of lay and professional navigators within a system of care.

Defining PN is further complicated by other programs that use community health workers to perform similar, but not necessarily the same, roles as navigators.²⁴ This review found

practice location and population focus to be key determinates of how these functions were defined. PN most often described clinic/hospital-based services, while community-based programs included community health workers, navigators, and/or advisors. Even more, community-based programs tended to focus on specific racial/ethnic or rural groups in contrast to PN programs that focused on urban, low income and mixed racial/ethnic participants despite sharing goals of reducing barriers to care and improving outcomes for un-/underserved populations. These differences were noted in another review of navigation in federally qualified health centers where community health workers focused on community-based interventions and included other titles such as lay health advisor, promotora, case manager, community outreach specialist, lay health educator, and lay health worker.²⁵ Once more, PN was situated in clinical settings, although the study grouped these roles to assess their impact on service care delivery.

Cancer Education

Cancer education is a specialized area of research and practice that is a key component to patient-centered care involving the participation of not only the patient and provider, but a much larger network of the cancer care team and patients' friends and families.²⁶ Critical components of cancer education consist of stakeholders, content, organization, and challenges. Stakeholders range from basic scientists to personnel that interact with cancer patients and their providers. It relies on the needs of the patients and their families in conjunction with the expertise of cancer care teams, rather than a paternalistic approach of experts determining what patients and their support system need to know.²⁷ Content consists of specialized knowledge and training for purveyors of this resource.²⁶ While much of this expertise resides in cancer care teams, interests in diversifying educational opportunities to broader audiences calls for the incorporation of cancer prevention and screening education beginning in school settings to instill cancer

education a lifelong learning opportunity.²⁸ In addition, opportunities must exist outside of traditional institutions to incorporate communities in need of cancer education leveraging experts and trainees to reach underserved communities.²⁹

Within organizations, cancer education should be adapted to the institution, incorporate best practices, coordinated among providers, and able to be evaluated in a systematic manner.²⁶ Thus, it requires a great deal of time and effort to achieve optimal results. However, these efforts are limited by challenges, the last component of patient-centered cancer education. First, funding models need to be developed to ensure adequate implementation. Accessibility also poses challenges, and finally the field is in need of greater dissemination of best practices.

Rurality

This project considers counties as rural, frontier, or border based on U.S. Census definitions of metropolitan and non-metropolitan areas that correspond to rural and urban categories.³⁰ In addition, border and non-border designations are based on the La Paz Agreement of 1983 between the U.S. and Mexico defining counties that are within 100 kilometers of the U.S./Mexico border as “border counties”.³⁰ Consequently, these definitions form the basis of the designations of rurality and rural residents used in this study.

Still, the concept of “rural” remains in debate by various governmental agencies and researchers.³¹⁻³³ The variation of definitions based on population concentration, proximity to metropolitan areas results in complex resource allocations for social services that create methodological concerns for evaluation and practice.^{33,34}

Given these differences, cancer outcomes for rural and urban comparison are difficult to measure.³⁵ Some evidence points to variation in cancer incidence between rural and urban

residents; however, the evidence suggests that cancer-related outcomes are best understood by defining rural as the distance between residents and health providers and variation of screening, which appears higher for urban residents as they are in closer proximity to providers.³⁵ Other evidence supports rural disadvantage with cervical cancer incidence ranging from 6% to 15% higher for rural residents compared to urban counterparts.³⁵ Similarly, invasive breast cancer incidence has decreased by approximately 14% among women in urban areas while only about 8% for rural women.³⁵ These findings implicate screening as a major component contributing to this variation highlighting other literature that shows lower breast and cervical cancer screening for rural women that is even lower for women of color in comparison to non-Hispanic whites.^{36,37}

Literature Review

Systematic reviews of health literacy³⁸ and patient navigation³⁹ interventions to promote breast and cervical cancer screening highlight programs around the country that increased screening uptake using evidence-based interventions, yet the majority of these programs focus on urban settings with little consideration of environmental factors as a possible independent variable affecting screening outcomes. Given the unique challenges that rural women may encounter when seeking breast and cervical cancer screening, a systematic review of quantitative research and a narrative review of qualitative research were conducted to identify studies that analyze education and patient navigation interventions to increase screening among rural populations. This study seeks to identify and compare programs aimed at improving mammogram and Papanicolaou (Pap) screening rates considering the negative findings regarding poor screening, late-stage diagnoses, and higher mortality rates for rural women.

Methods

A mixed methods review was conducted to identify studies that analyze education and patient navigation interventions to increase screening among rural populations. For the quantitative review, a comprehensive search of Pubmed, Medline, the Cochrane Library, PsycINFO, and Web of Science was conducted to identify applicable studies. As initial searches specifying breast and/or cervical cancer prevention education and patient navigation interventions in rural areas yielded few results, the key terms rural, breast, and cervical were expanded using medical subject headings (MeSH). Inclusion criteria consisted of U.S.-based, English-language articles published between January 1990 to December 2016 that examined an education and/or patient navigation intervention using a control or comparison group and measured changes in screening completion as the main outcome.

Meanwhile, the qualitative review included a search of six databases (PsycINFO, PubMed, Medline, CINAHL, EBSCO, and Healthsource) for publications ranging from January 2000 to December 2016 using key terms including “rural, breast, cervical, cancer, prevention, screening, patient navigation, and qualitative.” To reflect on social work literature specifically, other sources were selected from reviews of applicable journals including but not limited to, *Qualitative Health Research*, *Psycho-oncology*, the *Journal of Psychosocial Oncology*, *Social Work in Health Care*, *Health and Social Work*, *Social Work in Public Health*, *Qualitative Social Work*, and *Research on Social Work Practice*. References lists of selected publications were also reviewed to identify additional relevant articles.

Inclusion criteria for qualitative findings consisted of U.S.-based studies published in English employing a qualitative methodology to examine attitudes, behavior, or PN programming related to breast and cervical cancer screening among a sample of rural women. Exclusion criteria consisted of (1) studies that focused on program development or implementation, and (2) studies of rural women’s experiences following a cancer diagnosis.

Theoretical Framework

The Theory of Reasoned Action (TRA) provides the theoretical framework used to categorize the qualitative results and is often employed in health behavior research including breast cancer screening (see Fig. 1.1).^{40,41} TRA posits that a behavior is preceded by an intention to perform a behavior in which an individual’s attitude and subjective norm are directly related to the outcome.^{41,42} Behavioral beliefs and evaluations of behavioral outcomes are components of attitude, while normative beliefs and motivation determine subjective norm. Together, internal processes that determine attitude coupled with environmental qualities influencing subjective norm provide a measure of the intention to perform a behavior. TRA’s

focus on how attitudes and behavioral intentions predict behaviors aptly conceptualizes the focus of the studies included in this review.

Results

Quantitative Findings

A total of 2,280 records were identified from database searches (See Fig. 1.2). Titles and abstracts for each record were evaluated with 341 qualifying for full-text review and 1,939 excluded based on the initial assessment. A closer examination of 329 articles during the full-text review were rejected for failing to meet eligibility criteria, resulting in 12 publications included in the final analysis. Screening outcomes varied by test performed as five studies exclusively focus on breast cancer prevention, while the remaining studies are divided between cervical ($n = 2$) and multi-cancer ($n = 5$) prevention interventions. The articles also vary by type of intervention as eight are exclusively health education interventions and four more studies include patient navigation.

Randomized control trials. Table 1.1 compares the reviewed quantitative studies across eight dimensions. The references are organized by study design. The first four are randomized control trials with two separate publications disseminating findings from the same research study.⁴³⁻⁴⁶ An education program for Latinas aged 50+ measured significantly higher odds of mammogram and Pap screening for intervention participants compared to a control group.⁴⁴ The study was conducted in one rural county in Arizona along the U.S.-Mexico border. A community-wide intervention compared rural farmworker communities in eastern Washington.⁴⁶ Some communities received breast, cervical, and colorectal cancer screening education from the individual to organizational level, while others acted as control

communities. No significant differences were found between the groups as penetration of the intervention may not have matched the sample surveyed.

Paskett et al.⁴⁵ and Katz et al.⁴³ reported separate findings from the same intervention for mammogram and Pap screening, respectively. Both studies found significant increases in screening rates among intervention participants compared to control groups following a theory-based, lay health advisor education program on mammography screening. The study was limited by possible cross-contamination of participants.

Quasiexperimental studies. Four articles tested interventions to increase mammogram screening in three southern states using a breast health education and patient navigation interventions.⁴⁷⁻⁵⁰ Two publications analyzed the same intervention in northern Louisiana where health centers were separated into three test groups: enhanced care, education alone, education with nurse support.^{47,48} Nurse support increased mammogram screening in both papers. The authors report variation among the participants in each arm prior to the intervention risking possible outcome bias. The next study analyzed rural counties in North Carolina to test a lay health advisor intervention that demonstrated significant increases in mammogram screening rates among intervention counties compared to control counties.⁴⁹ The study measured many ways of exposing women to the screening message that were included in the analysis. However, this method limited the study's ability to measure the intervention effect. Finally, Powell et al.⁵⁰ compared churches demonstrating increased mammogram screening among participants who received education plus navigation, though it was limited to one, rural county in Alabama with possible cross-contamination among participants.

Two screening education studies demonstrated increased mammogram and Pap screening rates for intervention participants compared to comparison groups.^{51,52} A county-level, church-

based intervention in eastern Arkansas trained survivors as educators to promote mammogram screening showed significant increases in screening rates compared to usual care groups.⁵¹ Intervention participants were more often church attendees compared to those not receiving the intervention, leading to possible selection bias. An educational intervention using a lay health adviser found significant increases in mammogram and Pap screenings for intervention participants compared to participants not receiving the programming.⁵² Participant location was used in a random effects model to control for variation between the test and control communities.

The last two quasiexperimental, education interventions included in the review experienced null outcomes.^{53,54} A study analyzed mammogram screening outcomes in three eastern Michigan counties receiving a community-wide education intervention with a comparison county in a different part of the state.⁵³ Pre- and posttest measures recorded screening rates that did not vary significantly between intervention and control counties. A cervical cancer education program for Latina farmworkers in southeastern Georgia changed screening knowledge but did not affect screening uptake.⁵⁴ This article represented the only small study (N = 90) reviewed, which may account for the null finding as larger samples could detect more subtle effects.⁵⁴

Qualitative Findings

Initial searches of qualitative literature yielded 234 articles for detailed review based on their title. A review of the abstracts narrowed the selection to 93, and full-text review of these articles resulted in a final sample of 18 publications selected for inclusion. Studies were analyzed thematically using TRA constructs. After assigning applicable constructs to each article, content analysis of the studies' findings revealed emerging themes grouped under each

TRA domain. Table 1.2 organizes the studies by first author and year with a description of the study purpose, the sample size, setting, main findings, and associated TRA constructs.

Behavioral Beliefs

Medical mistrust. The studies varied in how the women graded their confidence in the medical system. Most often, it presented as mistrust directed at medical care impeding their screening behavior.⁵⁵⁻⁵⁷ However, trust in providers was also viewed as engendering positive attitudes towards screening,⁵⁵ while others noted that interventions should aim to reduce medical mistrust, particularly among minority communities.⁵⁸ A unique finding on medical mistrust came from Leach et al.⁵⁹ who describe a sense of alienation from providers due to patients' perceptions of feeling judged due to excessive weight or smoking habits.

Prior experiences. While one researcher situated medical mistrust proceeding experiences with the health care system,⁵⁷ others indicated that prior experiences determined women's attitudes towards screening. Kelly et al.⁶⁰ found that worry associated with a direct cervical cancer experience that evoked negative attitudes towards screening. Similarly, Purtzer et al.⁶¹ found that former immobilizing and isolating cancer experiences impeded screening behavior. Meanwhile, several studies cited similar themes related to prior negative experiences with health care or cancer influencing decisions not to screen among varying samples of women.^{58,62-64}

Lack of knowledge/awareness. This construct manifested as lack of knowledge surrounding breast health and screening⁶⁴⁻⁶⁶ as well as lack of awareness of the risk associated with breast cancer.^{57,65} Specifically, Filippi et al.⁶⁵ uncovered a complete lack of risk association, while Purtzer's⁵⁷ finding that women had a low perception of risk was more

nuanced. Head et al.⁶⁴ also extended lack of knowledge not only to screening as in the case of Filippi et al.⁶⁵ and Hubbell,⁶⁶ but also to the human papilloma virus (HPV) and vaccination for cervical cancer.

Fear. Three publications noted fear of cancer-related death as a barrier to screening.⁶⁷⁻⁶⁹ Tejeda et al.⁶⁹ also described fear in terms of the perceived physical pain associated with mammograms. Engelman et al.⁶⁷ distinguished fear among Hispanic women in comparison to non-Hispanic women.

Normative Beliefs

Culture. As evident in Table 1.2, these studies sampled from a broad range of rural communities with distinct cultural backgrounds and identities. Not surprisingly, culture emerged from different applications of its effect on normative beliefs. Canales et al.⁵⁵ examined the impact of American Indian identity on screening behavior. Language differences and its negative impact on provider communication was also apparent in another review.⁷⁰ Finally, two studies offered a more positive perspective that breast health educational materials⁵⁸ and preventative health communication⁷¹ should be culturally tailored to the receptive population for maximum impact.

Community. Interpersonal connections often associated positive intentions towards screening. Three studies found similar results of these relationships facilitating screening.^{56,63,69} Findings also suggested leveraging these interpersonal relationships in order to disseminate cancer screening knowledge.⁷¹ In contrast, two studies in Appalachian Kentucky found negative views of interpersonal relationships as they discouraged cancer screening.^{64,72}

Embarrassment. Three studies uncovered feelings of shame as a barrier to screening.^{64,67,68} The first study associated embarrassment with Hispanic women due to cultural views on modesty, noting that some women would only allow female health care providers to perform breast exams.⁶⁷ Another study cited feelings of vulnerability and exposure during a Pap test but did not mention provider-related associations.⁶⁸ Finally, social stigma against women who use public and reproductive health services negatively impacted cervical cancer screening in another study.⁶⁴

Control beliefs

Resources/cost. Access to care hindered by cost, lack of health insurance, and/or geographic location was the most salient theme cutting across most studies included in the review. Overwhelmingly, cost was cited as a primary impediment to screening.^{55,57-59,64,65,68,69,71,72} Costs were measured holistically in terms of the screening exam, follow-up care, ancillary testing and fees, and opportunity costs during screening and possible future treatment. Lack of transportation, scarcity of providers, and geographic isolation also factored into screening intentions.^{56,59,62-64,66,70} Finally, one source specified access in terms of excessive time to screening and a fragmented system of care.⁷⁰

Provider Communication. Two findings illustrated how provider communication moved the locus of control away from the individual towards the professional.^{63,67} In the first, women were concerned about how providers communicated during the procedure and reporting the results following the exam.⁶⁷ Meanwhile, another sample of women deemed provider communication as having both positive or negative effects on screening intentions and assessed their quality of care based on provider interaction.⁶³

Limitations

The lack of eligible studies limited the type and scale of analysis performed on the available data. Variation among the sample limited conclusions regarding the effect of the interventions as pooling data to calculate an aggregate statistic on the effect of these interventions was inappropriate. While not assessed quantitatively, publication bias also threatens the validity of the review's outcomes as articles with negative or null findings are often not published. The studies with null results for screening outcomes included in this review found some significant evidence of difference among comparison groups though they did not significantly improve screening rates.

The inclusion of PN and rural among the search terms narrowed the available qualitative scholarship. By doing so, it reveals a gap in the literature on the topic that currently receives more attention from other disciplines. Yet the findings from the reviewed studies identify psychosocial barriers addressed most often by clinical professions often not trained in behavioral practice. Moreover, the taxonomy of PN and limiting the scope to rural areas may simply underestimate social work's contribution to the literature.

Table 1.1

Education and/or patient navigation intervention studies to increase breast and cervical cancer screening among rural women from 1990 to 2016 (n=12)

<u>First Author</u>	<u>Study design & setting</u>	<u>Sample size</u>	<u>Screening outcome</u>	<u>Outcomes (+, -, 0)</u>	<u>Intervention</u>	<u>Behavioral Theory</u>	<u>Cancer type</u>
Nuño ⁴⁴	RCT, Yuma Co., AZ	381	Mammogram and Pap	+	Education	SCT	Breast, cervical
Thompson ⁴⁶	RCT, eastern WA	2,083	Mammogram and Pap	0	Education	None	Breast, cervical
Paskett ⁴⁵	RCT, Robeson Co., NC	851	Mammogram	+	Education	SCT, TTM	Breast
Katz ⁴³	RCT, Robeson Co., NC	775	Pap	+	Education	SCT, TTM	Cervical
Davis ⁴⁷	Quasiexperimental, northern LA	744	Mammogram	+	Education, PN	SCT, HBM	Breast, colorectal
Davis ⁴⁸	Quasiexperimental, northern LA	1,181	Mammogram	+	Education, PN	SCT, HBM	Breast
Earp ⁴⁹	Quasiexperimental, eastern NC	801	Mammogram	+	Education, PN	SEM	Breast
Powell ⁵⁰	Quasiexperimental, Greene Co., AL	197	Mammogram	+	Education, PN	None	Breast
Erwin ⁵¹	Quasiexperimental, eastern AR	410	Mammogram	+	Education	Locus of Control, TTM	Breast
Fernandez ⁵²	Quasiexperimental, TX-Mexico Border & CA Central Valley	707	Mammogram and Pap	+	Education	None	Breast, cervical

Table 1.1, cont.

Gardiner ⁵³	Quasiexperimental, eastern MI	1,545	Mammogram	0	Education	None	Breast, skin
Luque ⁵⁴	Quasiexperimental, southeastern GA	90	Pap	0	Education	None	Cervical

Note: HBM-health belief model, PN-patient navigation, SCT-social cognitive theory, SEM-socio-ecological model, TTM-transtheoretical model

Table 1.2

Qualitative studies of breast and cervical cancer screening for rural women from January 2000 to October 2016 (n = 18)

First Author	Purpose of Study	Sample size & Setting	Main findings	TRA constructs
Canales ⁵⁵	Explicate factors influencing mammography decision making	20 Rural and urban VT	Factors included native identity, self-care, health care finances, and medical mistrust	Beliefs, norms, control
Daley ⁵⁸	Understand barriers to mammography for American Indian women	66 Rural KS and MO	Barriers included Prior negative experiences with health care, need for culturally adapted educational material, interventions to improve medical mistrust	Beliefs, norms
Ely ^{72*}	Identify barriers to follow-up cervical cancer care	519 Appalachian KY	Individual, systemic, and community barriers were identified	Beliefs, norms, control
Engelman ⁶⁷	Analyze differences in mammography experiences between Hispanic and non-Hispanic women	88 Rural and urban KS	Hispanic women noted embarrassment and fear, while non-Hispanic women were concerned with provider communication	Beliefs, norms, control
Erwin ⁶²	Understand opportunities and barriers for cancer screening among Latinas	112 Urban NY, rural and urban AR	Country of origin and geographic residence determined perspectives on community-based religious organizations, experiences with the healthcare system, and access to services	Beliefs, control

Table 1.2, cont.

Filippi ⁶⁵	Examine perceptions of breast cancer screening among young American Indian women	48 Rural and urban KS	The sample were unaware of risks, lacked screening knowledge, and worried about the cost of screening	Beliefs, control
Head ⁶⁴	Understand young women's perspectives on cervical cancer prevention	19 Appalachian KY	Barriers included beliefs about prevention, lack of knowledge, normative influences, and geographic isolation	Beliefs, norms, control
Hubbell ⁶⁶	Determine breast cancer screening factors among Mexican American women	48 Rural NM	Barriers included lack of transportation, health care access, and screening knowledge	Beliefs, control
Kelly ⁶⁰	Understand the role of worry in cervical cancer screening	24 Appalachian OH	Direct experiences with cervical cancer engendered negative feelings towards screening	Beliefs
Leach ⁵⁹	Identify barriers to cervical cancer screening among middle-aged and older women	25 Appalachian KY and WV	Barriers included financial concerns, lack of resources, and alienation from health care providers	Beliefs, control

Table 1.2, cont.

Lyttle ⁶⁸	Understand attitudes about breast and cervical cancer screening	69 Appalachian WV	Primary barriers included cost, fear, and embarrassment	Beliefs, norms, control
McMillan ⁵⁶	Understand rural working women's perceptions of breast health	42 Appalachian TN	Barriers included medical mistrust and access to care, positive interpersonal connections facilitated healthy behavior	Beliefs, norms, control
Pinzon-Perez ⁷⁰	Identify determinants of Pap screening for Latinas	51 Rural Central Valley CA	Barriers included excessive time to screening, fragmented system of care, and language differences	Norms, control
Purtzer ⁵⁷	Discover the process of rarely or never-screened women's mammogram decisions	17 Rural WY	Factors influencing screening decisions included social isolation, medical mistrust, and perception of low risk	Beliefs, control
Purtzer ^{61*}	Investigate catalysts of mammography screening	25 Rural WY	Immobilizing and isolating cancer experiences impeded screening, while motivation and self-efficacy were associated with screening	Beliefs
Sentell ⁷¹	Investigate health communication challenges among Native Hawaiians and Filipinos	77 Rural HI	Suggested improvements included leveraging the role of interpersonal relationships in dissemination of cancer information and local, culturally tailored communication	Norms

Table 1.2, cont.

Tejeda ⁶⁹	Explore barriers and facilitators of mammogram screening among lower educated Mexican women	40 Rural WA	Barriers included lack of insurance, perceived physical pain, and fear; positive interpersonal relationships facilitated screening	Beliefs, norms, control
Torres ⁶³	Understand factors associated with breast or cervical cancer screening among Latinas	45 Urban NY, rural and urban AR	Prior health care involvement, access to resources, and communication impacted screening both positively and negatively; positive interpersonal relationships facilitated screening	Beliefs, norms, control

Note: TRA=Theory of Reasoned Action, *=Included at least one MSW-level author

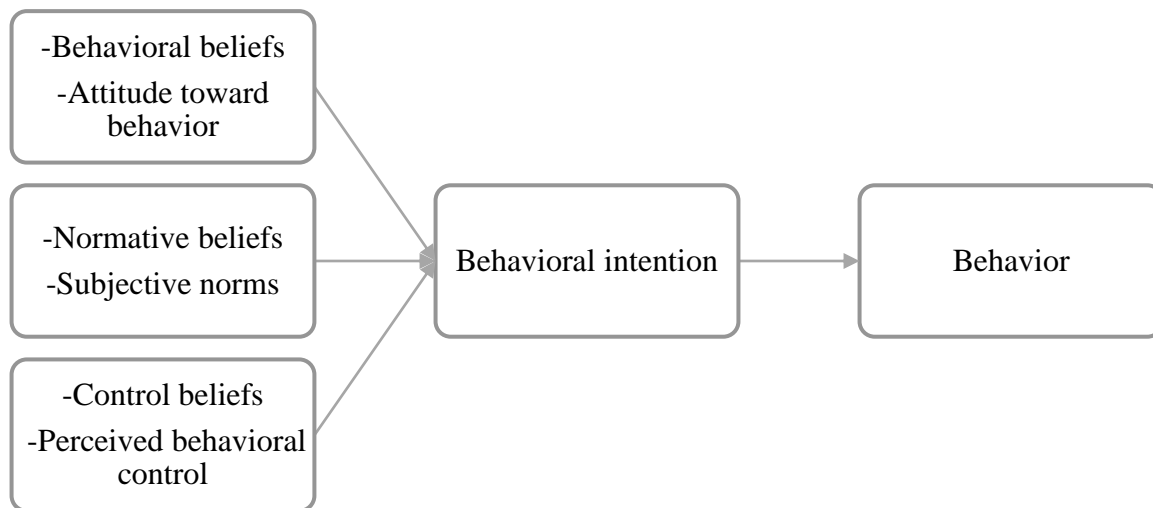


Fig. 1.1. Constructs of the Theory of Reasoned Action.

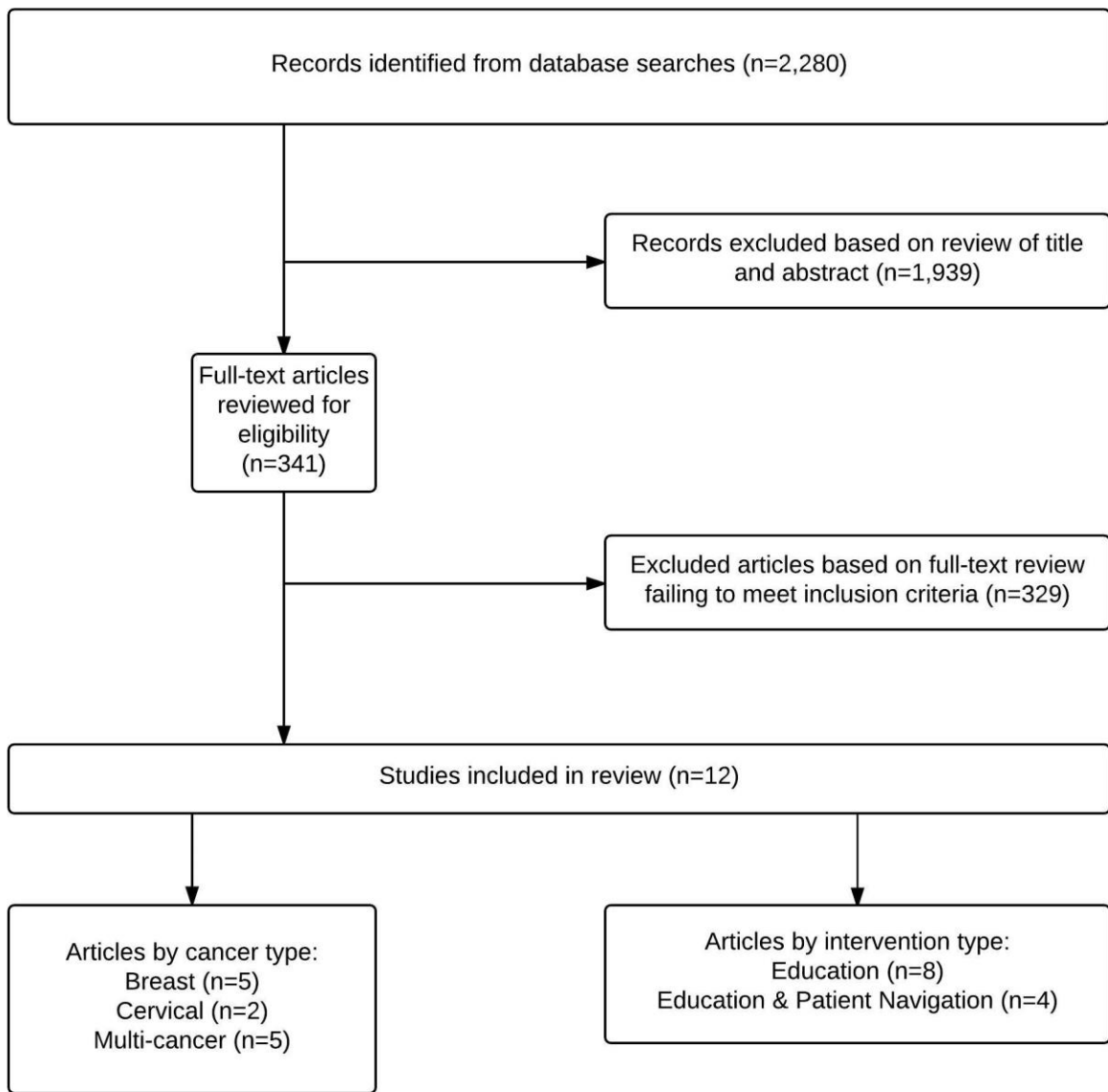


Fig. 1.2. Flowchart of quantitative study identification.

Chapter 2: Gaps in Research

Quantitative Gaps

With only 12 articles and 10 interventions over a 26-year period, the paucity of quantitative literature on breast and cervical cancer prevention interventions in rural areas using health education and/or patient navigation suggests a need for adaptation, implementation, and evaluation of evidence-based interventions in these areas. The study originally intended to compare the studies' effect sizes in a meta-analysis; however, the variation in design, interventions, and outcomes among the sample precluded a quantitative analysis. The sampled studies ranged in setting from Washington to Georgia, but most were in Southern states (n=9) compared with the few studies taking place in Western (n=2) or Midwestern (n=1) states and omitted many rural areas of the country completely. Only four articles and three interventions included patient navigation, which varied distinctly in implementation across the studies though all reported successful screening improvements. Similarly, education interventions ranged from a mailed pamphlet to individual, lay health advisor-led sessions at participants' homes. Consequently, outcomes from meta-analyses would provide little interpretive value due to the wide range of intervention approaches.

Still, the publications offer insight into tested programs for specific rural populations around the U.S. In that sense, the adaptation to community characteristics favors diverse interventions accommodating local variation. Most of the articles benefit from large sample sizes despite their rural setting. Also, all but five of the articles mentioned at least one behavioral theory as part of the conceptual framework of the intervention, yet the studies inconsistently related theoretical constructs to measurement tools. Of the articles failing to

mention a theory, three reported null findings while all studies including a theory reported screening improvements in intervention over control groups.

Finally, both health education and patient navigation interventions need greater theoretical refinement. The publications included in this study cited three behavioral theories for their conceptual frameworks. Nuño et al.⁴⁴ used social cognitive theory (SCT) exclusively, while Davis et al.^{47,48} combined SCT with the health belief model (HBM) to inform their intervention. The conceptual framework for the Robeson County Outreach Screening and Education Project employed SCT and transtheoretical (TTM) constructs,^{43,45} and the Witness Project used TTM and locus of control.⁵¹ A detailed conceptual framework allows for more critical evaluation of the studies' findings while connecting interventions to an established knowledge base. Analysis health education together with PN necessitates a theoretical framework that employs both SCT constructs rooted in observational learning with stages of changes garnered from TTM.

Additionally, rural areas need greater implementation and evaluation of screening interventions using health education and patient navigation as these services address the challenges of delivering high quality cancer care to populations in un-/underserved communities. The relative dearth of intervention studies on breast and cervical cancer education and patient navigation programs compared to urban studies highlights the need for validation of urban programs among diverse, rural populations.

Qualitative Gaps

Qualitative findings reveal intra- and interpersonal barriers to cancer care for rural women that require psychosocial support beyond traditional clinical services to truly provide person-centered cancer care. While patient navigation maintains a wide range of professional and non-professional roles, this study situates the knowledge, skills, and abilities developed in

social work education at the center of interventions that address comprehensive psychosocial needs for rural women beginning with screening. Still, this assessment faces practical challenges as qualified professionals capable of navigating these psychosocial barriers are scarcely available in rural areas. Health disparities will persist while systems of care remain static; however, transdisciplinary practice and technological advances may offer some solutions for social work education, practice, and research.

TRA offers a framework to understand the cognitive processes of rural women deciding (or not) to screen for breast and cervical cancer. These women provide insight into the decisional balance that precedes psychosocial needs post-diagnosis. Evidence from this synthesis points to psychosocial barriers that influence screening behavior underscoring the need for interventions that identify women at a pivotal stage to educate and connect them to services. To impact behavioral beliefs, interventions must address mistrust in the healthcare system often resulting from prior negative experiences. Also, they need education about their risk of these cancers and the benefits of screening. Regarding normative beliefs, community support consisting of direct interpersonal relationships can positively influence screening behavior intentions, and interventions must consider cultural variation in their design to have the greatest impact especially among racial and ethnic minority women. Finally, rural women are particularly concerned about the costs of screening and resources available to screen and receive continued care if they were diagnosed with cancer. At times, women simply are unaware of the assistance programs available to them; however, they also measure costs broadly including the opportunity costs if cancer was detected during screening and weigh these against the benefits of early detection. Thus, a comprehensive approach to encouraging these women to screen include care plans that mitigate these concerns.

Chapter 3: Implications for Social Work

Implications for Education

Multidisciplinary education feeds innovative practice methods to real-world settings as health care responds to complex issues in population health.⁷³⁻⁷⁵ The need for new educational paradigms have led to the development of online programs⁷⁶ with the potential to train students interested in pursuing social work in remote locations. In addition, dual degree programs in social work and public health⁷⁷ leverage overlapping areas of practice and research leading to innovative career paths for graduates.^{78,79} Finally, leadership in oncology social work have responded with continuing education initiatives for practitioners addressing areas including multidisciplinary collaboration while maintaining social work values of person-centered, culturally-sensitive, and evidence-informed practice.⁸⁰ Professional development opportunities include certification as an oncology social worker trained in clinical settings.⁸¹ Partnerships with other cancer care organizations such as the American Cancer Society, CancerCare, and the Lance Armstrong foundation broadens the impact of oncology social work to offer psychosocial services for all cancer patients.⁸¹

The experience and research of social work education has developed professional standards that guide human service functions from a theoretical and scientific basis that incorporate a multidisciplinary foundation in order to address a range of socioecological factors that contribute to an individual's health and wellbeing.⁸² Therefore, while outcomes research play an integral role in evaluating interventions, the complexities of human behavior are often reduced to compliance without deeper understanding of the psychosocial processes not only of those who "succeeded" in performing the desired behavior, but also those who fail to act as the intervention intends. Social work education and practice speak to the psychosocial needs of both

groups. Psychosocial oncology practice is best embodied by professional organizations such as the Association of Oncology Social Workers and the American Psychosocial Oncology Society that envisions high quality standards of care for cancer patients, families, and caregivers that address the range of their psychosocial needs.^{81,83} Their efforts specialize the field of psychosocial oncology with continuing education and certification denoting the unique qualifications that trained practitioners have developed to meet the needs of the patients and extended networks. Therefore, these individuals already model whole-person cancer care.

Implications for Practice and Research

Cancer-related disparities and population health outcomes have led to new leadership roles in accountable care organizations for social workers to leverage their experience to respond to this change.⁸⁴ Clinical settings such as those mentioned offer ideal locations to connect the community to the health care system. However, rurality again challenges this interface as hospitals with resources capable of prioritizing these activities often serve large regions.

Reaching rural women in need requires leveraging resources to bridge service gaps. Jang et al.⁸⁵ described isolation in terms of a linguistic community within an urban area and demonstrated positive behavioral outcomes using telecounseling services provided by social workers. This study connected highly specialized social workers with the required language skills to service clients at great distances. One limitation to this approach is rural access in areas where markets may not be conducive to major technological investment, thus creating a “digital divide” in comparison to urban areas.⁸⁶ As technology advances with greater smartphone use and continued research into telehealth and mental health services, incorporating these advances show promise for interventions involving geographically isolated individuals.⁸⁷⁻⁸⁹

Refinement of PN requires documenting roles and functions of current programs^{90,91} in a similar way that social work has developed a taxonomy for clinical social workers in multidisciplinary teams in clinical settings.⁹² While we can define these roles within our own profession, we must work collaboratively with other disciplines to articulate the value of social work's contribution to PN through continued practice and research.

The potential for genomics and precision medicine in cancer have an unclear impact on health disparities considering socioecological factors that contribute to gene expression;⁹³ nevertheless, oncology social work must consider the ethical, legal, and psychosocial issues while providing genetically and ethically informed practice to underserved groups.^{94,95} Formative research has identified psychosocial concerns of women with genetic predisposition for breast cancer^{96,97} shaping potential social work practice in genomics and broadening the definition of cancer prevention.

Chapter 4: Policy Environment

A range of national and state policies have created opportunities to improve cancer-related health outcomes for un-/underserved women by promoting breast and cervical cancer preventative screening while fomenting collaboration among various healthcare-related disciplines. However, policies have also presented more barriers to women's health negatively impacting breast and cervical cancer screening capacity. National legislation is presented in reverse chronological order to trace the development of policies, while state legislation is grouped thematically.

National Policies

The following legislation outlines the most influential policies affecting breast and cervical cancer prevention efforts at a national level. The chronologic progression illustrates how policy refinements resulting from research demonstrating the effectiveness of prevention interventions. Further, they represent the value of public investment in reducing the impact of these cancers for the population. This review also denotes the years of investment from policymakers and researchers to develop an increasingly comprehensive approach to prevent and treat breast and cervical cancer.

The Patient Protection and Affordable Care Act (ACA) of 2010. The ACA (2010) intended to expand healthcare access primarily through increased participation in health insurance among individuals formerly uninsured. Healthcare plans were now also required to include preventative health services, including mammograms and Pap tests, at no cost to participants in order to reduce barriers to preventative screening.⁹⁹ Insurance status has a high impact on preventative care utilization. For example, only 43.3% of low-income women without insurance in Texas have had a mammogram in the past 2 years compared to 71.4% of low-

income women with insurance based on data from the 2013 Behavioral Risk Factor Surveillance System (BRFSS).¹⁰⁰ Similarly, 67.7% of low-income women without insurance in Texas have had a Pap test in the past three years compared to 80.8% of low-income women with insurance.¹⁰⁰

The ACA (2010) expanded access to low income individuals by giving states funds to expand Medicaid through broader enrollment. Texas, however, opted not to participate in Medicaid expansion, resulting in a loss of approximately \$9.2 billion by 2022 in federal funding earmarked for expansion of these services for the state due to lost federal funds.¹⁰¹ As a consequence, millions of Texans who cannot afford insurance and would qualify for Medicaid in other states remain without insurance. This risks women's health as this policy translates to 687,000 Texan women (27.6% of uninsured Texan women) who are unable to access Medicaid as intended by the ACA.¹⁰⁰

The ACA (2010) improved healthcare access in other ways. Provisions included continued coverage for young adults, who can remain on their parent's health insurance policies until they are aged 26 years. This benefit reaches young women when they are at the greatest risk of becoming infected with HPV.¹⁰² Vaccinations, including those targeting HPV, are included in health plans at no cost sharing for participants. Access to these vaccines have the potential to greatly reduce the incidence of cervical cancer by targeting this known cancer-causing agent, yet evidence shows only 32% of the targeted population have opted for inoculation.¹⁰³

Cost of care is a major concern for individuals and families and has been noted as a key barrier for cancer patients seeking treatment.^{104,105} Out-of-pocket expenses for care worried over a third of cancer patients, while 37.1% reported being concerned about bankruptcy due to cancer

treatment.¹⁰⁶ The ACA (2010) prohibited healthcare plans from setting lifetime limits on coverage and eliminated preexisting conditions as a reason for denying enrollment. Still, premiums, deductibles, and co-pays remain financial barriers to cancer treatment. Evidence supports these concerns as one study found that cancer patients had a 2.65 times higher odds of declaring bankruptcy compared to those without cancer.¹⁰⁷

Beyond insurance, the law outlined several priorities to improve population health. First, the ACA (2010) called for improved coordination and quality of healthcare. While these provisions are not specific to cancer care, they touch on issues common in the cancer care continuum. This mandate underlines the challenges that cancer care providers may face such as disjointed services, complex treatments, and rising costs.¹⁰⁸ The ACA (2010) also addressed health disparities.¹⁰⁹ Medicaid expansion is cited as a primary means to reduce disparities as the impact directly affects people of color, who represent over half of the currently uninsured.¹¹⁰ Also, it provided for increased data collection on race, ethnicity, primary language, disability status, and gender and extended civil rights nondiscrimination laws to healthcare providers receiving federal funding. The law expanded the National Health Service Corps, which provides funding and placement of health professionals to areas where shortages exist.¹⁰⁹ Community health workers, including patient navigators, are also funded to provide culturally and linguistically appropriate services to underserved areas.

Patient Navigator Outreach and Chronic Disease Prevention Act of 2005. The Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 resulted from the work of oncologist Harold Freeman.¹³ Recognizing the barriers faced by African American (AA) women of low socioeconomic status (SES) in cancer treatment, Freeman developed a PN program to improve cancer-related outcomes.¹¹² The program provided free screening and PN

services to medically underserved men and women living in Harlem. Outreach and educational programming helped identify at-risk individuals and recruit them into care services. By identifying and removing barriers for patients,¹¹³ screening rates improved and contributed to the development of policies culminating in this legislation.¹¹⁴

The law authorized the establishment of the National Cancer Institute's (NCI) Center to Reduce Health Disparities to fund demonstration projects using Freeman's model.¹⁰⁴ Since then, over 300 programs funded by NCI and the ACS were found to use this model to increase cancer screening among racial and ethnic minorities and low SES individuals.^{115,116} The ACA (2010) reauthorized funding for the act and cites PN explicitly as a means to reduce disparities for racial/ethnic groups, eliminate barriers to care, and integrate healthcare systems for improved outcomes. While reducing disparities remains the ultimate goal of this and other initiatives, research thus far has focused primarily on identifying groups with disparate outcomes and testing interventions aimed at increasing screening and treatment for these groups.¹¹⁷

The Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA) of 2000.

The BCCPTA (2000) functions in tandem with the Breast and Cervical Cancer Mortality Prevention Act (BCCMPA) as Breast and Cervical Cancer Services (BCCS) to provide treatment services to women diagnosed with breast and cervical cancer. This legislation funds Medicaid expansion for women diagnosed with pre-cancer or cancer so that they can seek treatment without the concern of cost. Each location (state, territory, or tribal area) determines the level of need required to access Medicaid via this program.¹¹⁹ However, all states had implemented this optional program by 2005 thereby paving the way for women of low SES to access breast and cervical cancer care. While Medicaid enrollment lengthens the treatment initiation time to

approximately 2 weeks, the additional time is unlikely clinically significant and worth the tradeoff of covering cancer care expenses.

These complementary policies echo elements ACA (2010). Full coverage of preventative services, expansion of healthcare coverage, and goals of reducing disparities while improving outcomes show evidence of continued development towards improving cancer care, especially for low SES, minority women.¹²⁰ Despite this seeming overlap in coverage, the latter programs remain important to women's health as the lack of Medicaid expansion under ACA in some states still puts low SES women at risk. Even after implementation of the ACA (2010), the women served by BCCMPA and BCCPTA are estimated to increase.¹²¹ However, less than a third of women eligible for BCCMPA and BCCPTA access them.¹²² Eligibility criteria include residing in Texas, not having health insurance, aged 18+, and earning up to 200% of the Federal Poverty Level (FPL).¹²³ These two findings point to the need for interventions that reach out to women needing these services to raise awareness of available options, to screen, and then to treat those diagnosed with cancer.

The Breast and Cervical Cancer Mortality Prevention Act (BCCMPA) of 1990.

This law authorizes funds for the CDC's National Breast and Cervical Cancer Early Detection Program (BCCEDP). This program provides screening to un-/underserved elderly, low-income, and racial/ethnic minority women through a competitive grant review process.¹¹⁹ This law recognizes the unequal burden of cancer for women and disparities for racial and ethnic minorities compared to non-Hispanic white (NHW) women and aims to reduce morbidity and mortality for these cancers.¹²⁵ The provisions of the act include funding of public health agencies, state and territorial health departments, and American Indian and Alaskan Native tribes to screen and diagnose women for breast and cervical cancer.¹¹⁹ Furthermore, the program

includes case management services, data collection, outreach, and education services. As of 1997, the program had achieved participation from all 50 states, the District of Columbia, five territories, and 11 tribes. To qualify for Medicaid for Breast and Cervical Cancer (MBCC) in Texas, a woman must have a previous breast or cervical cancer diagnosis, need treatment, reside in the state, be a U.S. citizen or resident, be between 18-64 years of age, not have health insurance, and may earn up to 200% of the FPL.¹²³

The BCCMPA provided for screening services with the expectation that local agencies would contribute towards treatment once women were diagnosed.¹¹⁹ However, the need to fund treatment was recognized in further legislation due to concerns that individuals diagnosed were not receiving or delaying treatment because of cost. Thus, additional legislation made way for a more comprehensive approach to include un-/underserved women.

Population Research and Voluntary Family Planning Programs of 1970. Commonly referred to as “Title X” of the Public Health Service Act, this statute designates funding for family planning and preventative health services including access to cervical cancer screening. Assessments of Title X funding have found many positive results. Since its inception, cervical cancer has dramatically been reduced from the leading cause of cancer for women in the U.S. 40 years ago to now the 14th most common cancer diagnosis.¹²⁷ Pap tests are cited as the main reason for this change, and the lack of access to this preventative screening is considered the reason for disparate rates of cervical cancer incidence among population groups.¹²⁷

Cervical cancer screening along with the other services provided by Title X result in tremendous savings for government programs. In 2010, estimates reached \$13.6 billion in government savings translating to a return on investment of \$7.09 for every \$1 of public investment.¹²⁸ Clinical services account for the majority of spending under Title X at 90%.¹²⁹

Over 1.5 million screenings occurred at Title X service sites in 2011 with approximately 15% detecting pre-cancerous or cancerous lesions requiring further evaluation.¹³⁰

Title X funded service sites are also an essential resource for immigrant women as they are not required to verify their legal status.¹³¹ Furthermore, legal immigrants are barred from receiving Medicaid services for the first five years of residency, thus reducing their access to quality healthcare, while undocumented immigrants only receive Medicaid in emergency situations. Title X clinics also must provide linguistically appropriate care thereby facilitating their needs even more.

Despite the reduction of incidence of cervical cancer associated with the enactment of Title X programming,¹²⁷ congressional appropriations have continued to reduce its funding with some calling for the elimination of provisions completely.¹³² Since its inception, Title X has received a maximum of \$317 million in 2010 with levels declining since then despite the need for increased funding to adequately cover these services for women in need.¹³²

Texas Policies

Legislation in Texas follows similar patterns to national efforts regarding cancer control and prevention. Seeking to reduce the impact of cancer for individuals and reducing the economic burden to the state,¹³³ the first pieces of legislation discussed reference broad-based initiatives supporting cancer research and prevention efforts. Cervical cancer prevention, however, has suffered from a series of policies limiting resources due to its association with abortion and family planning services. These policies are outlined in the latter part of this section with a discussion regarding cervical cancer screening and access to women's health services.

Art. III, Sec. 67 of the Texas Constitution. In 2007, a constitutional amendment established the Cancer Prevention Research Institute of Texas (CPRIT)¹³⁴ as a funding mechanism to support innovative cancer research, including evidence-based interventions, through investment in higher education institutions and other public and private entities. Bonds totaling \$3 billion were issued to fund research and services with a goal of reducing the impact of cancer in the state while fostering innovative research by Texas-based researchers.

Beginning in 2009 and expiring in 2021, the grants fund basic science research, prevention interventions, commercialization of related drugs and devices, and other related services.¹³⁴ In 2014, over \$292 million were awarded through 169 grants with over 420,000 Texans benefitting from prevention and control services.¹³⁵ Of the active prevention grants in 2014, 34 grants addressed breast cancer while 26 included cervical cancer. Preventative screening and diagnostic exams was provided to over 433,000 Texans for breast, cervical, and colorectal cancer, and over 956,000 received education and training interventions. Texas' investment in cancer research is considered the largest source of non-federal public cancer funding in the U.S. Basic science research grants represented the largest share of funding expenditures at 54%, followed by funding for cancer treatment at 25%, and prevention interventions at 11%. The rest of the grant distribution included cancer etiology (6%), scientific model systems (2%), and cancer control, survivorship, and outcomes (2%). As of 2014, more than \$504 million has been awarded to fund scientific research in cancer biology, treatment, and prevention.

CPRIT grant funding was suspended for a 10-month period due to questionable allocation of funding.^{136,137} Despite recommendations from scientific review, several grant applications were denied in lieu of ones with commercial merit.¹³⁷ The controversy led to a criminal

investigation and the resignation of Alfred Gilman, Nobel laureate and former chief scientific officer of the agency.¹³⁷ In 2013, grant funding was continued after oversight changes.¹³⁸

S.B. No. 53. The Legislative Task Force on Cancer in Texas established the Texas Cancer Council in 1985 through strategic legislation aimed at reducing the burden of cancer in the state through coordination of public, private, and volunteer efforts.¹³⁹ The primary method of carrying out this mission is by means of the Texas Cancer Plan, focusing on prevention planning by promoting intervention programming that increases access, availability, and quality of resources for screening and diagnostic services.¹⁴⁰ This legislation was a precursor to the establishment of CPRIT, which has since been mandated with the continuation of the Texas Cancer Plan and funding prevention and other cancer-related research previously described.

S.B. No. 1051. Mirroring the passage of the federal Patient Navigator Outreach and Chronic Disease Prevention Act of 2005, the Texas legislature formalized the rules for community health workers in 2015 with S.B. No. 1051.¹⁴¹ S.B. No. 1051 defines community health workers as:

A person who, with or without compensation is a liaison and provides cultural mediation between health care and social services, and the community. A promotor(a) or community health worker: is a trusted member, and has a close understanding of, the ethnicity, language, socioeconomic status, and life experiences of the community served. A promotor(a) or community health worker assists people to gain access to needed services and builds individual, community, and system capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, patient navigation and follow-up, community health education and information, informal counseling, social support, advocacy, and participation in clinical research.¹⁴¹

H.B. No. 2. House Bill No. 2 (2013) enacted several restrictions on abortion services in Texas.¹⁴³ The law requires doctors performing abortions to have admitting privileges at hospitals within 30 miles of the clinic, bans abortions after 20 weeks, requires women to attend two separate doctor's visits prior to receiving abortion-inducing drugs and one visit 14 days following the appointment. In addition, later amendments require abortion facilities to be ambulatory surgical centers. The added regulation of these services has caused a steady decline of qualifying clinics from 25 as of March 2014 to 18 as of June 2015 with only eight of these locations operating as ambulatory surgical centers.¹⁴⁴ A U.S. Supreme Court case found these laws to be unconstitutional as they do not improve women's safety but result in greater restrictions for women seeking abortions.¹⁴⁵

S. B. No. 747. Passed in 2015, this law makes it illegal for facilities providing family planning services to receive Medicaid funding. It targets Planned Parenthood because they provide abortions to women, thus forcing them to close and limiting access to other sexual health services, such as Pap screening, particularly for low-income women who rely on Medicaid.

S.B. No. 7. This previous law enacted in 2012 stops the use of taxpayer funds for abortion services. Together with the previous mentioned legislation, they represent a concerted effort to restrict abortions for women in Texas. By attacking Planned Parenthood, however, it weakens cancer prevention efforts by eliminating another provider of Pap tests and other sexual health services for un-/underserved women.

Legislation in process. Texas continues to impose limitations on abortion access intended to harm women's health organizations. Senate Bill 8 includes a ban on fetal tissue donation, requires fetal tissue to be buried or cremated, bans a common abortion procedure, and bans private insurance coverage for elective abortions.¹⁴⁶ The fetal tissue burial or cremation

requirement has already faced legal challenges with a U.S. district judge ruling the requirement unconstitutional. Also, Senate Bill 4 prevents government entities from partnering with abortion providers and their affiliates.¹⁴⁶

Policy Implications

Resources such as Planned Parenthood and other organizations serve a vital role in healthcare for underserved populations, yet political views on women's health have impacted their health and safety. H.B. No. 2 and similar laws are touted as an effort to protect women's health through higher standards for facilities providing abortion; however, eliminating one of the few community partners serving women's health imperils their access to cervical cancer screening and other sexual health services, including human immunodeficiency virus (HIV) screening. Limiting providers has decreased mammogram and Pap screening by 14 to 23 percent among Latinas in Texas while no significant change was found for NHW women.¹⁴⁷ Lower educated women also screened at lower rates under these new policies.¹⁴⁸ Other studies have found a decrease in contraception coupled with an increase in childbirth rates covered by Medicaid.¹⁴⁹

For social workers and allied professions, these policies do not frame a cohesive approach towards increasing screening among un-/underserved women as some policies conflict directly with the aims of others. However, they provide some tools to advance health equity. The policy gaps also highlight areas where research and practice offer solutions to improve community health. To help shape supportive policies, legislators and the public must be educated about the benefits to greater health care access.

Chapter 5: Overview of the Three Papers[‡]

Paper 1: Increasing Breast and Cervical Cancer Screening in Rural and Border Texas with Friend to Friend plus Patient Navigation

Introduction

Racial/ethnic minority and rural women experience lower screening rates and delays in mammograms and Papanicolaou (Pap) tests compared to non-Hispanic white (NHW) women and urban residents leading to a greater cancer burden for these individuals.^{36,37} Diagnostic and therapeutic delays may lead to greater treatment difficulty and increased cost for both the individual and healthcare system as breast is the leading and cervical is the fourth leading cancer diagnosis among women nationally and in Texas.¹ Early detection of breast and cervical cancer through screening may improve survival and decrease mortality rates by detecting malignancies at a non-invasive stage, resulting in more successful treatment.² As a result, improving the wellbeing of underserved communities by reducing the impact of these cancers for minority and rural women remains a priority for policy makers, researchers, and clinicians.¹⁵⁰

Researchers have developed interventions aimed at improving screening rates for racial/ethnic minority and rural women through health education and patient navigation (PN).^{151,152} PN, an evidence-based practice within the cancer care continuum and other diseases, is a patient-centered healthcare delivery model that utilizes trained lay navigators to integrate a

[‡]A version of the first paper in this chapter was previously published prior to the dissertation defense. The committee reviewed and accepted this article for inclusion in the dissertation. The dissertator contributed to the design, performance, analysis, and writing of the article. The other authors reviewed and supplied technical expertise. The dissertation committee determined the contribution by the dissertator and content were acceptable for inclusion in the dissertation. The material is reprinted with permission from the American Association for Cancer Education, Springer.

Falk, D., Cubbin, C., Jones, B., Carrillo-Kappus, K., Crocker, A., & Rice, C. (2016). Increasing breast and cervical cancer screening in rural and border Texas with Friend to Friend plus Patient Navigation. *Journal of Cancer Education*, 1-8. doi: 10.1007/s13187-016-1147-6

fragmented system of care in order to reduce barriers to timely care for individuals and subsequently reduce disparities for population groups.¹⁰⁴

The objective of this paper is to evaluate programmatic outcomes of a health education and PN intervention for rural women in Texas by identifying sociodemographic and other screening-related factors that (1) distinguish participants who chose PN services from those who did not (non-PN); and (2) were associated with receiving a mammogram or Pap test.

Intervention

In 2010, the Texas A & M AgriLife Extension Service was awarded outreach education funding by the Cancer Prevention Research Institute of Texas (CPRIT) to adapt the evidence-based program, *Friend to Friend* (FTF) in rural and border counties in Texas.¹⁵³ FTF consists of “pink parties” targeting an audience of lower income, un-/underinsured women aged 40+ who may be disabled, self-employed, and/or have limited English proficiency (LEP).

The CPRIT funding supported hiring four, fulltime equivalent regional cancer prevention specialists to work with county extension agents to organize local work groups of women to deliver the FTF program and educate women about the need for mammograms and Pap tests. However, the funding did not allow for follow-up or active support for women to obtain the screenings. To address these issues and increase the number of women screened, clinical services funding was sought and awarded by CPRIT, allowing the addition of four fulltime equivalent patient navigators to join the team of regional cancer prevention specialists, payment for clinical services when needed, and transportation services.

The purpose of the, now, *Friend to Friend plus Patient Navigation* Program (FTF+PN) is to build an effective, sustainable infrastructure and overcome barriers to breast and cervical screening and diagnostic services to increase screening rates for underserved, un-/under-insured,

and older women in approximately 50 rural and border counties. The goal is to increase the number of women screened according to American Cancer Society (ACS) guidelines for breast and cervical cancer, thereby increasing the probability any cancers detected would be diagnosed in earlier stages. At the time, ACS guidelines recommended annual mammograms for women aged 40-54 and biannual mammograms for those aged 55+ with average risk of breast cancer.¹⁵⁴ For cervical cancer screenings, recommendations included Pap tests every 3 years for women aged 21-29 and every 5 years for women aged 30-65 with no additional screenings needed for women aged 65+ if their previous results were normal.¹⁵⁵

Methods

This prospective study analyzed program evaluation data collected from FTF+PN participants and events from March 1, 2012 to February 28, 2015. The Institutional Review Board (IRB) of The University of Texas at Austin reviewed and approved (FWA # 00002030) the proposed study prior to analysis. Data included responses to pre- and post-test surveys of the education intervention (FTF) and follow-up surveys of screening behavior by non-PN and PN participants, totaling N = 2,689 unique respondents meeting inclusion criteria for the final analytic sample. The sample included women aged 18 to 99, who self-identified exclusively as African American (AA), Latina, and NHW. Individuals indicating multiple race/ethnicities (n = 123), American Indian or Native American (n = 29), Asian, Asian-American, or Pacific Islander (n = 20), and other race/ethnicity or missing (n = 21) were excluded due to small sample sizes. Also, subsequent responses for women attending multiple parties (n = 346) were excluded.

Two survey items identify Latinas. The first asked the respondent to identify their race/ethnicity, with “Latino, Hispanic, Chicano, Mexican or Mexican-American, Central American, or other Latin American” as one response option. The second asked about primary

language used at home. Primary language use at home, conceptualized as a marker of acculturation, distinguished Latinas who only spoke English (Latina ES; n = 399) from those who only spoke Spanish or used Spanish and English equally (Latina SS; n = 1,261). Language accounts for most of the explained variance in studies of acculturation measures,¹⁵⁶ and brief, language-based measures of acculturation have been validated among Latino groups with English or Spanish language preferences.¹⁵⁷ This variable helps to distinguish nuances among Latina participants using an available survey item approximating this measure. Thus, four demographic groups were defined according to race/ethnicity and acculturation (AA, Latina ES, Latina SS, and NHW).

Dependent variables recorded on the follow-up surveys included PN status, receipt of mammogram screening, and receipt of Pap screening. Each FTF participant was offered a “help request form” to indicate the need for PN and screening services following the education program. Respondents providing contact information on the posttest survey and/or help request were subsequently interviewed by patient navigators to determine if they received a mammogram or Pap test. The total number of contacts, summing the number of direct contacts (calls, emails, texts, etc.) with a participant and indirect contacts made on behalf of a participant (calls, emails, texts, etc. coordinating services with providers made by the patient navigator or regional cancer specialist that did not include the participant), were also noted on the follow-up survey. Those not providing contact information on the posttest survey or help request and those who had not completed a follow-up interview were excluded from the analysis (See Table 5.1).

Several independent variables from the pretest and posttest surveys were included in the analysis. The pretest captured the respondents’ demographic data including race/ethnicity (self-identified exclusively as AA, Latina, or NHW), primary language use at home (English only,

Spanish only, or English and Spanish equally), age (calculated based on year of birth), and education level (categorized as did not complete high school, high school graduate, or some college or more). Participants also self-reported mammogram and Pap test history (dichotomized as receiving a mammogram or Pap test prior to FTF+PN or not) in addition to the main reason for attending FTF (need help paying for tests, came with friend/family member, family history of cancer, doctor/nurse said tests were needed) on the pretest. Individuals reported barriers to screening on the posttest with options including worry about cost, transportation, not having time, problems with child/elder care, nervousness about testing, bad experiences getting care, testing not offered where they live, not knowing where to go, problems getting through the application process for assistance programs, or other reason. All analyses were conducted using SPSS software, version 21 (IBM Corp., Armonk, NY). Findings were considered statistically significant using 2-tailed *P* values of less than .05, .01, and .001.

Results

Table 5.1 presents the number of sample participants by race/ethnicity and follow-up status. NHWs were the largest group represented (45.2%) followed by Latina SS (37.5%), Latina ES (12.6%), and finally AAs (4.8%). The sample was further separated by PN cases (27.7%), non-PN cases (37.9%), and those with no follow-up (34.5%) who either omitted contact information effectively closing their case or were still awaiting follow-up at the time of the analysis.

Table 5.2 provides descriptive statistics of independent variables for the two follow-up categories (PN and non-PN cases) by race/ethnicity. Women aged 40 to 64 consistently represented the largest proportion of PN and non-PN participants in each racial/ethnic category reflecting the goal of FTF+PN as well as ACS guidelines for women most in need for

mammogram screening.¹⁵⁴ Latina SS women reported the lowest educational achievement for both PN cases (63.1%) and non-PN cases (39.2%). PN participants designated cost as the reason for attending at much higher rates compared to non-PN respondents. Finally, PN participants received mammogram and Pap screenings after the FTF event at much higher rates compared to non-PN respondents.

The logistic regression model results for odds of PN status, mammogram screening, and Pap screening appear in Table 5.3. The first step of the PN hierarchical model identifies that all sociodemographic variables significantly impact PN status. Older women had lower odds of being a PN participant, women of color had 2.4 to 8.5 higher odds of being a PN participant compared with NHW women, and women with lower levels of education had higher odds of being a PN participant compared with women with at least some college education. The second step of the model includes additional screening-related variables. Age, race/ethnicity, and education remained statistically significant, and respondents reporting cost of screening or that a health professional advised them to attend as a reason for attending a FTF+PN event had higher odds of being a PN participant compared with women who did not endorse those reasons. Women reporting a barrier to screening also had higher odds of being a PN participant compared with women reporting no barriers (OR = 4.42, CI = 3.30-5.93). Finally, women reporting that they attended a FTF+PN event because a friend or family member was attending had lower odds of being a PN participant compared with women who did not endorse that reason.

The logistic regression models for mammogram screening follow the PN status models. In the sociodemographic model (Step 1), older and Latina SS women, and those with lower education had higher odds of receiving a mammogram compared with their respective reference groups. In the second step of the model including screening-related factors, Latina SS women

were no longer statistically significantly different from NHW women in the odds of screening, but Latina ES women had lower odds of screening compared with NHW women. Women with a history of a screening and those who came to FTF primarily because a doctor or nurse say that the test was needed had higher odds compared with women with no history and who did not select a doctor or nurse's recommendation as the main reason for attending. Cost of screening as a reason for participating in a FTF+PN event was associated with 1.8 higher odds of receiving a mammogram compared to those not endorsing that reason. Also, both being a PN participant (OR = 2.64, CI = 1.02-1.91) and respondents with more contacts (OR = 1.14, CI = 1.11-1.17) had greater odds of receiving mammograms compared with non-PN participant status and women with fewer contacts.

Finally, Table 5.3 presents logistic regression models for getting a Pap test at follow-up in the last two columns. In the sociodemographic model, older women had lower odds, and Latina SS women and those with lower education had higher odds of receiving a Pap test compared with younger, NHW, and college educated women. Once the screening-related factors were added in Step 2, older women still had lower odds compared with younger women, and Latina SS women still had higher, although attenuated odds, compared with NHW women. However, Latina ES women were found to have lower odds of receiving a Pap test compared with NHW women and the education odds were no longer statistically significant. As with mammograms, participants indicating cost as a reason for attending a FTF+PN event had higher odds of receiving a Pap screening (OR = 1.80, CI = 1.40-2.32) than those not endorsing this reason. PN participants also had higher odds of receiving a Pap test compared to non-PN participants (OR = 2.72, CI = 2.00-3.69), and a greater number of contacts was associated with

higher odds of receiving a Pap screening compared to those with fewer contacts (OR = 1.13, CI = 1.10-1.17).

Of women in the follow-up sample who received a mammogram, 201 had an abnormal finding, 103 received a diagnostic screening, and 22 women were diagnosed with breast cancer. For Pap tests, 70 women had an abnormal finding, 14 received a diagnostic screening, and eight women received a cervical cancer diagnosis. The grant provided funding for continued navigation and clinical services following screening if the women did not qualify for other programs such as Breast and Cervical Cancer Services (BCCS), Medicaid, private insurance, or other options.

Discussion

The results of this study yield several promising findings regarding the impact of adding PN to the FTF health education program to increase breast and cervical cancer screening among women in rural Texas. Participation in PN was associated with an increase in the odds for both mammogram and Pap screenings. In addition, more contacts to the participants themselves or on their behalf increased the odds for screening in these same models. These variables illustrate that PN status and follow-ups are clear points of intervention that can be leveraged to increase the likelihood of participants in FTF+PN to screen successfully for breast and cervical cancer and reflect similar successes reported in preventative screening PN programs. Comparable studies include a promotora-based intervention that significantly increased mammograms in a randomized sample of 381 women living in the United States-Mexico border region of Arizona.⁴⁴ A quasi-experimental study of 1,181 rural women in Louisiana reported higher odds of mammogram screening for those receiving navigation compared to women receiving health education only.⁴⁸

The FTF+PN program was successful in reaching its intended target population of women who are at higher risk of unfavorable breast and cervical cancer outcomes¹⁵⁸ and who could benefit from PN services. Rural women of color, those with lower education, those who attended FTF because of concerns about screening cost, and those reporting a barrier to screening had higher odds of being a PN participant compared with their reference groups. While ACS guidelines for mammogram and Pap tests^{154,155} have a limited age range compared to the sample, the intervention did not exclude any participants aged 18+ based on recommendations as women outside of these ranges may need services depending on their individual health status and history. Instead, we chose to include all adults and to control for age for increased power and a consistent sample size. Furthermore, this intervention leverages aspects of social cognitive theory that describes the role of observational learning in behavioral performance through positive reinforcement.¹⁵⁹ Peer networks, including friends and family, model a behavior that the individual incorporates through observation into their own behavior. Observational learning increases self-efficacy, the individual's belief in her ability to get screened for breast and cervical cancer, as these women learn from interpersonal and community role models. As indicated in Table 5.3, 31-49% of women identified attendance to FTF with a friend or family member as the main reason for participating. Women often attend FTF with friends and relatives, respond to the pre- and posttest, but may not seek screening. Thus, these women have lower odds of being a PN participant. Still, FTF educates women of all ages to increase health literacy of these cancers that may affect them directly or other women in their social networks. In sensitivity analyses, we re-ran the logistic regression models according to ACS age guidelines (aged 40 years and over for mammogram screening, aged 21-65 years for Pap screening) and found similar results.

A main reason for attending FTF+PN was needing help paying for the screening(s). Participants had to connect with a patient navigator or regional cancer prevention specialist in order to pay for the screenings using the funds provided by CPRIT or from other programs of which participants may have been unaware, such as BCCS, other screening programs, private insurance, etc. Despite mandates for full coverage of breast and cervical cancer screening costs under the Affordable Care Act (ACA), additional supportive services are needed to help increase breast and cervical cancer screening for women who remain uninsured after ACA's implementation and still face cost as a barrier to screening.¹²² Therefore, FTF+PN is providing a safety net for rural, low SES women to access mammograms and Pap tests, as Medicaid coverage was not expanded in Texas to increase insurance coverage for the uninsured poor living between 101-133% of the federal poverty level (FPL). The program aimed to provide screening services to un-/underinsured women; however, insurance status was not recorded systematically although navigators may have collected this information from some participants during their initial intake. Future analyses of this data should include measures of health insurance status at the county-level.

Advice from a medical service provider has been demonstrated to increase preventative cancer screening.¹⁶⁰⁻¹⁶² Though this variable was significant in the regression on mammogram screening and not for Pap screening, advice from a nurse or doctor as a reason for attending FTF was associated with nearly a threefold increased odds ($OR = 2.54$) in choosing PN (see Table 5.3). This finding highlights the impact of medical provider advice on shaping screening behavior by increasing the readiness of these women to take a step towards screening. Consequently, medical providers must be aware of current prevention recommendations in order

to provide accurate health education to their patients based on risk factors including age and family history. This duty is compounded by the evolving nature of the recommendations.

Latina ES women experienced higher odds of PN status and lower odds of receipt of a mammogram or a Pap test compared to NHWs after controlling for other important sociodemographic and screening-related factors. These findings are in contrast with the experience of Latina SS women, who also had higher odds of PN status, but no differences in receipt of a mammogram, and *higher* odds of a Pap screening compared to NHWs. Separate logistic regressions were also conducted with Latina SS as the reference group to compare the outcomes between Latina ES and SS women directly (see Table 5.4). This positive finding for less acculturated Latinas is important to highlight as Latinas experience much higher incidence and mortality rates of cervical cancer compared to other groups in Texas; further, this finding appears to substantiate the “Hispanic paradox” theorized as the protective effect of immigration on health as less acculturated Latinos born outside the U.S. consistently exhibit lower morbidity and mortality compared to U.S. born Latinos and NHWs.¹ However, data regarding country of origin and time living in the U.S. was not collected from this sample; thus, this effect can only be suggested by the limited measure of acculturation based on language. Although the FTF+PN data cannot differentiate Latinas into heterogeneous subgroups, census data indicate 87% of Latinas in Texas are of Mexican origin.¹⁶³ It may be possible that regional differences in PN efforts and providers may have accounted for the differences, or that the PNs were more successful at navigating SS women compared with ES women for reasons that would require further research.

While AAs experienced greater odds of PN status compared to NHWs, there was no significant difference in their receipt of mammogram or Pap screening compared to NHWs in the adjusted models, indicating that navigation was successful for these women, or at least as

successful as it was for NHWs. While not considered in the statistical analysis, the success in screening AA women may be due in part to racially and culturally congruent intervention staff able to reach women in their community. This finding demonstrates the success of the intervention considering observational studies that indicate lower breast and cervical cancer screening rates for AA women compared to NHW women after controlling for sociodemographic variables in both urban³⁷ and rural¹⁶⁴ settings. Other population-based¹⁶⁵ and rural¹⁶⁶ studies point to lower screening rates and later stage breast cancer diagnosis for AA women compared to NHWs.

The results of this study include several limitations. First, the study sample is non-representative as there was a concerted effort to target women who were lower SES, and un- or under-insured. There is no way to determine whether the FTF+PN sample is representative of all lower SES and un-/under-insured women in these rural counties. All evaluation instruments recorded information based on self-report with possible recall bias a potential limitation. As noted in Table 5.1, 35% of the FTF+PN participants had not completed a follow-up interview, though comparisons of these respondents with those in the follow-up sample did not reveal any substantial differences. Also, program implementation differed in each of the four regions. The role of the patient navigator and cancer prevention program specialist varied by region, and protocols of when and how to follow-up may not have been consistent across regions. Ideally, the study aimed to measure time from FTF participation to screening; however, delays in contracts with providers and protocol variations threatened measurement fidelity of this variable. Finally, we had a very limited measurement of SES (i.e., educational attainment) in our study. We were unable to examine other measures, such as income, wealth, and/or occupational status.

Despite these limitations, the study includes a large sample of women living in rural and border areas within the second largest state by area and population in the U.S. Given the large Spanish-speaking population involved in the study, the FTF+PN program and survey materials were available in Spanish. Furthermore, several of the patient navigators and program assistants are bilingual to assist monolingual Spanish speakers and bilingual Spanish speakers with LEP.

The data from the evaluation of FTF+PN lends itself to further analysis in order to determine additional factors that may be related to breast and cervical cancer screening outcomes for this sample. This analysis lays the groundwork for future studies nesting participants by county and region to develop a multilevel model testing the effects of ecological variables on PN participation and mammogram and Pap screening outcomes.

Conclusion

PN is an effective intervention approach to increase breast and cervical cancer screening among women in rural and border Texas. The study's findings add to the evidence base that demonstrate the positive impact of PN on mammograms and Pap tests in varied settings across the U.S. The analyses suggest that FTF+PN successfully captures participants who are underrepresented in breast and cervical preventative screening (rural women, women of color) and suffer poorer cancer-related outcomes.

Table 5.1

Friend to Friend + Patient Navigation participants, 3/1/12-2/28/15, by race/ethnicity and follow-up status (N =4,104)

<u>Race/ethnicity</u>	<u>Follow-up</u>		<u>No follow-up</u>	<u>Total, n (%)</u>
	<u>PN cases</u>	<u>Non-PN cases</u>		
African American	43	60	92	195 (4.8)
Latina English Speaking	205	194	119	518 (12.6)
Latina Spanish Speaking	1,076	185	276	1,537 (37.5)
Non-Hispanic White	230	696	928	1,854 (45.2)
Total, n (%)	1,554 (37.9)	1,135 (27.7)	1,415 (34.5)	4,104 (100.0)

PN=patient navigation

Table 5.2

Characteristics of patient navigation (PN) and non-patient navigation (non-PN) follow-up respondents of Friend to Friend + Patient Navigation, 3/1/12-2/28/15 (N =2,689)

Variable	PN follow-up cases				Non-PN follow-up cases			
	AA	Latina ES	Latina SS	NHW	AA	Latina ES	Latina SS	NHW
Race/ethnicity (n)	43	205	1,076	230	60	194	185	696
Age category (%)								
18-29 years	11.6	12.1	5.7	6.5	0.0	10.7	10.7	4.1
30-39 years	11.6	19.1	17.7	12.6	0.0	17.6	20.3	10.6
40-64 years	72.1	61.8	71.7	68.7	61.8	58.8	44.1	49.5
65+ years	4.7	7.0	4.9	12.2	38.2	12.8	24.9	35.8
Education level (%)								
Did not complete high school	11.6	19.0	63.1	21.0	13.3	9.6	39.2	3.7
High school graduate or GED	44.2	36.5	24.4	31.1	28.3	31.9	26.5	23.8
Some college or more	44.2	44.5	12.5	47.9	58.3	58.5	34.3	72.5
Screening history								
Reported mammogram prior to FTF (% Yes)	51.2	55.4	58.4	63.3	91.5	68.9	64.4	80.5
Reported Pap prior to FTF (% Yes)	73.8	91.7	88.5	90.7	86.7	93.3	85.0	92.9
Main reason for attending FTF:								
Need help paying for tests (% Yes)	55.8	68.8	77.6	60.4	1.7	8.2	21.6	5.5
Came with friend/family member (% Yes)	34.9	31.2	33.1	32.6	35.0	35.6	49.2	39.2
Family history of cancer (% Yes)	34.9	39.0	28.2	41.3	38.3	24.7	27.6	32.0
Doctor/nurse said tests were needed (% Yes)	14.0	13.2	20.0	10.0	1.7	3.1	2.7	2.3
To find out more about tests (% Yes)	25.6	31.7	49.0	31.3	38.3	39.7	42.7	21.6
Reported barrier to screening (% Yes)	86.0	92.2	90.4	85.2	40.0	52.6	52.4	43.7
Number of contacts (Mean)	8.2	8.4	9.3	5.5	2.2	2.6	2.6	2.5
Received mammogram screening (% Yes) ^a	55.8	44.9	60.4	39.1	15.0	10.8	9.7	28.0
Received Pap screening (% Yes) ^a	51.2	48.3	68.9	33.9	6.7	6.2	8.6	16.1

Note. Percentages based on total number of responses received by each racial/ethnic group for each item. AA=African American; ES=English speaking; SS=Spanish Speaking; NHW=non-Hispanic White.

^a Depending on the help request, some received both mammogram and Pap tests, while others only received one screening.

Table 5.3
Odds of patient navigation status, mammogram screening, and Papanicolaou (Pap) screening among follow-up respondents, Friend to Friend + Patient Navigation, 3/1/12-2/28/15 (N =2,689)

Variable	Patient Navigation Status		Mammogram Screening		Pap Screening	
	Step 1 OR (95% CI)	Step 2 OR (95% CI)	Step 1 OR (95% CI)	Step 2 OR (95% CI)	Step 1 OR (95% CI)	Step 2 OR (95% CI)
Age	0.97 (0.96-0.98)***	0.97 (0.97-0.99)***	1.03 (1.03-1.04)***	1.04 (1.03-1.05)***	0.98 (0.97-0.99)***	0.99 (0.98-1.00)*
Race/Ethnicity						
African American	2.38 (1.51-3.76)***	3.03 (1.74-5.29)***	1.23 (0.75-2.03)	0.91 (0.52-1.57)	1.54 (0.92-2.58)	1.03 (0.57-1.86)
Latina English Speaking	2.36 (1.80-3.09)***	1.99 (1.42-2.79)***	1.08 (0.81-1.45)	0.60 (0.43-0.83)**	1.23 (0.92-1.65)	0.66 (0.47-0.92)*
Latina Spanish Speaking	8.48 (6.57-10.94)***	6.77 (4.91-9.35)***	2.53 (1.98-3.22)***	0.93 (0.69-1.25)	4.15 (3.24-5.31)***	1.64 (1.22-2.20)**
Non-Hispanic White	ref.	ref.	ref.	ref.	ref.	ref.
Education level						
Did not complete high school	4.58 (3.46-6.07)***	2.39 (1.68-3.39)***	1.94 (1.52-2.47)***	1.25 (0.94-1.65)	1.64 (1.28-2.11)***	0.88 (0.66-1.17)
High school graduate or GED	2.21 (1.74-2.79)***	1.59 (1.18-2.13)**	1.35 (1.08-1.70)*	1.01 (0.78-1.31)	1.29 (1.02-1.63)*	0.87 (0.66-1.14)
Some college or more	ref.	ref.	ref.	ref.	ref.	ref.
Reported mammogram prior to FTF		1.10 (0.79-1.52)		2.29 (1.80-2.92)***		
Reported Pap prior to FTF		0.92 (0.59-1.42)				1.36 (0.96-1.91)
Main reason for attending FTF:						
Need help paying for tests		11.84 (8.87-15.81)***		1.75 (1.35-2.28)***		1.80 (1.40-2.32)***
Came with friend/family member		0.73 (0.57-0.95)*		0.91 (0.74-1.11)		0.89 (0.72-1.10)
Family history of cancer		1.14 (0.87-1.49)		0.94 (0.77-1.16)		0.99 (0.80-1.23)
Doctor/nurse said tests were needed		2.54 (1.43-4.53)**		1.39 (1.02-1.91)*		1.09 (0.79-1.49)
To find out more about tests		0.95 (0.73-1.24)		1.09 (0.88-1.34)		1.02 (0.83-1.26)
Reported a barrier to screening		4.42 (3.30-5.93)***		0.97 (0.75-1.27)		1.21 (0.91-1.60)
Patient navigation status (PN v. non-PN)				2.64 (1.93-3.60)***		2.72 (2.00-3.69)***
Number of contacts				1.14 (1.11-1.17)***		1.13 (1.10-1.17)***

* $P < .05$, ** $P < .01$, *** $P < .001$

Table 5.4

Odds of patient navigation status, mammogram screening, and Papanicolaou (Pap) screening among follow-up respondents, Friend to Friend + Patient Navigation with Latina Spanish Speaking as the reference group, 3/1/12-2/28/15 (N =2,689)

	<u>Patient Navigation Status</u> OR (95% CI)	<u>Mammogram Screening</u> OR (95% CI)	<u>Pap Screening</u> OR (95% CI)
Age	0.97 (0.97-0.99)***	1.04 (1.03-1.05)***	0.99 (0.98-1.00)*
Race/Ethnicity			
African American	0.45 (0.25-0.79)**	0.98 (0.56-1.71)	0.63 (0.35-1.13)
Latina English Speaking	1.99 (1.42-2.79)***	0.64 (0.47-0.89)**	0.40 (0.29-0.55)***
Non-Hispanic White	6.77 (4.91-9.35)***	1.08 (0.80-1.45)	0.61 (0.46-0.82)**
Latina Spanish Speaking	ref.	ref.	ref.
Education level			
Did not complete high school	2.39 (1.68-3.39)***	1.25 (0.94-1.65)	0.88 (0.66-1.17)
High school graduate or GED	1.59 (1.18-2.13)**	1.01 (0.78-1.31)	0.87 (0.66-1.14)
Some college or more	ref.	ref.	ref.
Reported mammogram prior to FTF	1.10 (0.79-1.52)	2.29 (1.80-2.92)***	
Reported Pap prior to FTF	0.92 (0.59-1.42)	-	1.36 (0.96-1.91)
Main reason for attending FTF:			
Need help paying for tests	11.84 (8.87-15.81)***	1.75 (1.35-2.28)***	1.80 (1.40-2.32)***
Came with friend/family member	0.73 (0.57-0.95)*	0.91 (0.74-1.11)	0.89 (0.72-1.10)
Family history of cancer	1.14 (0.87-1.49)	0.94 (0.77-1.16)	0.99 (0.80-1.23)
Doctor/nurse said tests were needed	2.54 (1.43-4.53)**	1.39 (1.02-1.91)*	1.09 (0.79-1.49)
To find out more about tests	0.95 (0.73-1.24)	1.09 (0.88-1.34)	1.02 (0.83-1.26)
Reported a barrier to screening	4.42 (3.30-5.93)***	0.97 (0.75-1.27)	1.21 (0.91-1.60)
Patient navigation status (PN v. non-PN)		2.64 (1.93-3.60)***	2.72 (2.00-3.69)***
Number of contacts		1.14 (1.11-1.17)***	1.13 (1.10-1.17)***

* $P < .05$, ** $P < .01$, *** $P < .001$

Paper 2: County-level Poverty and Barriers to Breast and Cervical Cancer Screening in a Health Education and Patient Navigation Intervention for Rural and Border Texas

Residents

Introduction

Breast and cervical cancers broadly impact women's health with more than 280,000 new diagnoses and nearly 46,000 cancer-related deaths reported in 2018,¹⁶⁷ yet social determinants affect morbidity and mortality outcomes differently for varying groups of women.¹⁶⁸ For example, rural women's lower screening rates compared to urban residents' rates may lead to later stage diagnoses and higher mortality rates for both types of cancer.^{3,5} Even more, women in rural counties with high poverty rates screen for breast cancer at much lower rates than their urban counterparts, and these differences are compounded for women of color when compared to urban and white residents.¹⁶⁹ Studies of residents living in the Texas-Mexico border region reflect similar findings with lower cancer screening and higher cancer-related mortality in lower socioeconomic status (SES) areas compared to higher SES areas with additional variation by race/ethnicity favoring NHW women.^{169,170} Other comparisons of racial/ethnic groups demonstrate higher breast cancer mortality rates for African American (AA) women than for non-Hispanic white (NHW) women and higher cervical cancer mortality rates for both AA and Latina women than for NHW women associated with differences in access to screening and high-quality cancer care, varying rates of poverty, access to insurance, longer follow-up for diagnosis and treatment, among other possible factors.¹⁶⁸ As a result of these findings, targeted cancer care delivery beginning with detection has resulted in interventions for un-/underserved women with the goal of connecting them to timely care to improve both individual and population outcomes.²

In 2012, the Texas Agrilife Extension Service established *Friend to Friend plus Patient Navigation* (FTF+PN) with grant funds from the Cancer Prevention Research Institute of Texas (CPRIT) to increase breast and cervical cancer screening among women aged 40+ who may be disabled, self-employed, and/or have limited English proficiency (LEP) residing in approximately 70 un-/underserved rural and border counties. Grant funds paid for clinical services and employed four trained, lay patient navigators that joined an established team of four regional cancer specialists to follow-up with program participants and provide transportation or other ancillary services that addressed barriers that might prevent women from screening. Patient navigators and regional cancer specialists worked in four regional teams where they organized bilingual, culturally sensitive cancer education incorporating local cancer care professionals and survivors from the community. The education program known as a “pink party” informed women about the need for timely breast and cervical cancer screening based on American Cancer Society (ACS) guidelines for breast and cervical cancer at the time recommending annual mammograms for women aged 40-54 and biannual mammograms for those aged 55+ with average risk of breast cancer¹⁵⁴ and Papanicolaou (Pap) tests every 3 years for women aged 21-29 and every 5 years for women aged 30-64.¹⁵⁵ Women attending the party were offered help getting screened at the end of the event using PN services to assist them with payment, transportation, or barriers that might prevent them from screening. Participants who provided contact information at any point during the intervention received follow-up interviews to assess their screening outcomes.

The following analysis examined the impact of county-level poverty rates on screening outcomes for participants attending the FTF events and reporting a barrier to screening. In doing so, it examines the intervention’s capacity to identify and connect individuals residing in the

poorest communities to screening services. By addressing both individual and community needs that may negatively impact screening outcomes, FTF+PN seeks to impact cancer-related outcomes for disadvantaged rural and border residents of Texas.

Methods

The analysis combines the proportion of adults living at or below the federal poverty level (FPL) for each county with individual-level variables from FTF+PN participants who attended the FTF and reported at least one barrier to screening. FTF+PN was implemented in 36 rural and border counties during 2012, and the following year saw an additional 23 counties served. In 2014, 5 more counties received the intervention for the first time. Finally, 7 novel counties were included in the program in 2015 and 5 more in 2016. Based on availability and demand, some counties had multiple parties within the same year and some held additional in subsequent years. In total, FTF+PN operated in 76 unique counties within four administrative regions and held over 180 separate FTF events from 2012 to 2016.

The individual-level data include responses to pre- and post-test surveys from FTF+PN participants during events and follow-up surveys of screening behavior from March 1, 2012 to November 5, 2016, totaling N=7,450 unique observations. The analytic sample first excluded women who had not received follow-up (n=1,451) as their screening status could not be determined. Women who did not report barriers to screening (n=1,667) were also excluded. In addition, 96 respondents reporting multiple or other racial/ethnic categories, women who identified as American Indian or Native American (n=29), Asian, Asian-American, or Pacific Islander (n=30), were excluded due to small sample sizes. Latinas were divided into two groups based on their language preference at home; therefore, those that spoke something different than English or Spanish (n=6) or missing this variable (n=50) were removed. Surveys with missing

age (n=95) and education level (n=189) were excluded. Finally, 545 participants who had attended repeated events were excluded for a total of N=3,292 included in the analytic sample. The Institutional Review Board (IRB) of The University of Texas at Austin reviewed and approved (FWA # 00002030) the proposed study prior to analysis.

Theoretical Framework

Andersen's behavioral model of health service utilization guides the conceptualization of this study to explain factors related to mammogram and Pap screening among intervention participants. The model describes the relationships among environmental and population characteristics that determine level of engagement with healthcare and subsequent health outcomes.¹⁷¹ Environmental factors include access to the healthcare system, availability of health services, and the external environment.¹⁷² Population characteristics describe predisposing characteristics (e.g., age and race/ethnicity), individual and community enabling resources, and both perceived and actual need.¹⁷² Mutability, or the degree to which these factors can be influenced to effect behavioral change, also plays a key role in the model design.¹⁷¹

Measures

County-level variables. The U.S. Census Bureau supplied aggregated data from the 2014 American Community Survey for county-level measure of poverty.¹⁶³ Percentages of the adult county population aged 18+ who lived below the FPL comprised the area SES measure. This variable was divided into tertiles ranked as low, medium, or high relative to the other counties involved in the intervention. Previous studies have found that residents of high poverty areas are diagnosed with more advanced stage cancer and have increased mortality from various

types of cancers including cervical and breast.⁴ More specifically, women in high poverty neighborhoods appear to have increased risk for cancer-related death underscoring the need for increased cancer screening in these areas.¹⁷³ Thus, this measure assesses FTF+PN participants' screening behavior relative to their residential location. Finally, the program operated in four administrative regions of the state (North, South, East, or West) adding an additional organizational level to the data.

Individual-level variables. The dependent variable consists of FTF+PN follow-up participants' receipt of a mammogram and/or Pap screening following the intervention. For the mammogram outcome, only women aged 40+ were included in the analysis based on ACS recommendations for an analytic sample of N=2,326. The Pap screening outcome sample was similarly reduced to women aged 21-64 based on ACS recommendations for a total of N=2,959 participants. Respondents provided demographic data including age (determined from their year of birth), race/ethnicity, primary language use at home, and education level (options included did not complete high school, high school graduate, or some college or more). Participants self-identified their racial/ethnic identity as AA, Latina, or NHW. Primary language use at home was defined as those who spoke English only, Spanish only, or English and Spanish equally. This variable was used to differentiate English speaking Latina (ESL) women from Spanish speaking Latina (SSL) women. Participants indicated if cost was the main reason for attending FTF, and their patient navigation status was recorded during follow-up interviews. The posttest captured potential barriers to screening with options including worry about cost, transportation, not having time, problems with child/elder care, nervousness about testing, bad experiences getting care, testing not offered where they live, not knowing where to go, problems getting through the application process for assistance programs, or other reason. This variable was used to select

those who reported a barrier to screening while excluding women who did not report any barrier from the analysis.

Statistical Analysis

The primary statistical analyses consisted of multilevel regression models using PROC GLIMMIX in SAS 9.4 (SAS Institute, Cary, NC). A series of logistic regression models analyze mammogram and Pap screening completion separately using fixed and random effects of individual and county level data. First, an intercept only model is used to calculate between-county variance. Then, fixed effects including age, race/ethnicity/language, and education level are added to the model. The next models include not attending FTF due to cost of screening, and not participating in PN. Finally, the county-level poverty ranking is considered in the final models.

Results

Results from the univariate analyses showed that mammogram and Pap screening prevalence rates were highest among women aged 40-64, SSL, and lower educated women as noted in Table 5.5. Over 41% of women with barriers did not attend the education intervention due to the cost of screening, and 26% of the sample chose not to participate in PN. Residents of counties with more than 19.2% of adults living in poverty represented the largest portion of the sample and had the highest screening prevalence rates for both tests. Similarly, the South region experienced the highest prevalence rates for both screenings and represented the largest portion of the sample.

The interclass correlation coefficients (ICCs) indicated significant variability in screening rates by county (results not shown). For mammogram screening, 3.29 was used as the level-1

error variance¹⁷⁴ and the county-level error variance was 0.84 for an $ICC = \frac{0.84}{0.84+3.29} = 20\%$. For Pap screening, the county-level error variance was 0.89 for an $ICC = \frac{0.89}{0.89+3.29} = 21\%$. Table 5.6 reported the results of the subsequent models with the added effects. Model 1 began with demographic variables including age, race/ethnicity/language categories, and education level. In the first model, AA and ESL women reporting a barrier to screening both experienced lower odds of screening with a mammogram compared to NHW women. This finding persisted across all models. Similarly, age and education level do not significantly impact any of the models.

In Model 2, two program related variables, not attending FTF due to cost of screening and not being a PN recipient, were included. This model revealed that women with barriers who were not concerned about cost and who did not participate also experienced lower odds of getting screened. Finally, the last model includes the county-level poverty variable which did not contribute any more to the model from the previous version. The model also increased the -2 log-likelihood statistic, indicating that the poverty level variable did not improve the model fit.

Table 5.7 reported the Pap screening models using the same progression of added effects. In the first, only education played a significant role with lower educated women with a barrier to screening experiencing higher odds than college educated women. However, this finding did not persist in Models 2 and 3, where women with barriers not attending FTF due to the cost of screening and not being a PN participant both had reduced odds of receiving a Pap screening. In addition, the last model indicated that counties with lower poverty rates experienced nearly double the odds of screening for cervical cancer compared to higher poverty counties.

Discussion

The findings from this study affirm PN as an effective intervention to increase screening uptake for both breast and cervical cancer. While individual-level variables indicated areas of programmatic success and specific groups of women still opting not to screen, the county-level results were less clear. For mammogram screening, variation based on county-level poverty did not appear to matter to screening outcomes despite county-level variability remaining significant in the model. On the other hand, Pap screening was higher in counties with fewer adults living in poverty, consistent with findings from other studies demonstrating the screening advantage for higher SES areas.¹⁶⁹

Despite their variation, the counties are high poverty in general, leading to less variation from county-to-county among higher SES, urban counties. The intervention's ability to maintain consistent screening rates across these boundaries, as is the case with mammograms, also speaks to the program's success of changing observed screening patterns in other studies demonstrating the advantages of higher SES areas. Thus, the lack of significant differences also points towards greater equity in screening provision among counties.

Finally, the results substantiate PN's effectiveness at increasing screening rates among this sample, especially among women concerned about the cost for screening. Mitigating financial barriers to care facilitated significant gains in screening rates among women with barriers to screening. PN factors directly into this finding as patient navigators facilitated payment for screening services and served other needs, such as transportation. Thus, PN practice in rural and border areas provides a responsive intervention to bridge gaps between health care systems and residents in need of cancer care services.

However, broad implementation of PN faces many challenges. First, PN services require funding from non-traditional sources as these services are not usually covered by health

insurance further straining resource limited safety net providers already struggling with reduced payments for reimbursable services.¹⁷⁵ Rural hospitals also contend with growing closures due to financial shortfalls further risking access to care among socioeconomically disadvantaged and racially/ethnically diverse communities.¹⁷⁶ While accreditation standards reflect the evidence base supporting PN by benchmarking best practices in cancer care, only institutions with the capacity to absorb the additional cost of PN can hope to adhere to this level of care.¹⁷⁷ Furthermore, shortages in cancer care professionals, rising treatment costs, and higher incidence rates of cancers among an expanding and aging population pose even greater challenges to health care systems required to respond with innovative practices while struggling to maintain their current capacity.¹⁷⁸

Despite PN's focus on the navigator as the primary means of intervening with patients, PN has also been described as a system of care involving both professionals in the cancer care community and outside the bounds of a health care institution.¹¹³ Consequently, the various individuals involved in PN and cancer care must understand their role as a part of PN to achieve the best outcomes for individual patients and the population. Multidisciplinary education for health professionals led by social workers, for example, offers a means to enhance clinical practice areas where the primary focus is not on treating psychosocial contributions to health and wellbeing but are often the primary professional contact for patients seeking screening and cancer treatment.⁸² By educating the health care workforce collaboratively, clinical professionals understand the role that allied professionals can contribute to reducing disparate outcomes from un-/underserved groups and leverage these resources to address barriers to care without diminishing their specific areas of expertise.

Limitations

While this study attempted to include multilevel factors influencing screening behavior, other elements not assessed in Andersen's model may also account for differences in screening by residential location, race/ethnicity/language, and other measures. Program implementation protocols varied by region so that patient navigators and regional cancer specialists could adapt to local conditions. Consequently, these differences may affect screening and participation rates in ways not assessed in this study as noted by the outcomes in the South region. At the time of the analysis, follow-up interviews had not been conducted on all intervention participants leading to possible bias in the results (see Table 5.8). Follow-up procedures varied from region to region leading to differences in follow-up screening rates. For example, the South region's additional patient navigator adding to their capacity to perform follow-up interviews at higher rates than the other regions. Also, participants from year 1 had a much longer timeframe to receive follow-up compared to participants in later years. Consequently, these practical limitations may have affected the results of the study.

Conclusion

Women with known barriers face multifaceted challenges to screening for breast and cervical cancer often leading to negative outcomes for the un-/underserved. Programs such as FTF+PN offer education and firsthand assistance for women to overcome these barriers to preventative care. This help extends to communities in need such as higher poverty counties in rural and border areas that benefit from these services. Still, not all participants benefitted equally as AA and ESL women screened lower for breast cancer than NHW women highlighting the need for further investigation into their screening decisions and barriers to care. To conclude, screening decisions are impacted by both individual and contextual factors that distinguish screening behavior among varying groups of women, and both should be considered

in the design and implementation of interventions aiming to improve health outcomes for un-/underserved groups.

Table 5.5

Sample distribution, mammogram, and Papanicolaou (Pap) screening prevalence rates of Friend to Friend + Patient Navigation follow-up respondents reporting one or more barriers to screening, 3/1/12-11/5/16.

Variable	Full sample (%) <u>N=3,292</u>	Prevalence of mammogram screening (%) <u>N=2,326</u>	Prevalence of Pap screening (%) <u>N=2,959</u>
Age			
21-39 years	28.5	-	46.8
40-64 years	62.4	56.4	48.4
65+ years	9.1	34.1	-
Race/ethnicity/language			
African American	4.0	34.6	26.0
English Speaking Latina	13.7	39.1	35.9
Spanish Speaking Latina	55.5	66.4	61.1
Non-Hispanic White	26.8	39.0	25.8
Education level			
Did not complete high school	38.4	64.6	59.3
High school graduate or GED	27.7	52.4	49.1
Some college or more	33.9	41.3	32.5
Region			
North	22.4	32.7	20.0
East	13.6	43.9	27.7
West	12.8	44.1	30.5
South	51.2	68.6	67.7
Did not attend FTF due to cost of screening	41.1	36.2	27.5
Not a patient navigation recipient	25.5	25.6	16.3
% county residents living in poverty			
1 st tertile, <14.2	19.3	41.5	39.0
2 nd tertile, 14.2-<19.5	19.7	37.5	28.8
3 rd tertile, 19.5+	61.0	62.3	56.2

Table 5.6

Mammogram screening models for Friend to Friend + Patient Navigation follow-up respondents aged 40+ reporting a barrier to screening (N=2,326), 3/1/12-11/5/16.

<u>Fixed effects</u>	<u>Model 1</u>		<u>Model 2</u>		<u>Model 3</u>	
	<u>Odds Ratio</u>	<u>95% CI</u>	<u>Odds Ratio</u>	<u>95% CI</u>	<u>Odds Ratio</u>	<u>95% CI</u>
Intercept						
Age						
40-64 years	ref.		ref.		ref.	
65+ years	0.76	0.57-1.02	0.94	0.70-1.27	0.94	0.70-1.27
Race/ethnicity/language						
African American	0.58*	0.36-0.93	0.58*	0.36-0.95	0.58*	0.35-0.94
English Speaking Latina	0.66*	0.46-0.94	0.59**	0.41-0.85	0.58**	0.41-0.83
Spanish Speaking Latina	1.13	0.83-1.55	0.97	0.71-1.33	0.96	0.70-1.31
Non-Hispanic White	ref.		ref.		ref.	
Education level						
Did not complete high school	1.29	0.99-1.68	1.18	0.90-1.53	1.18	0.91-1.54
High school graduate or GED	1.16	0.91-1.47	1.08	0.84-1.38	1.08	0.85-1.38
Some college or more	ref.		ref.		ref.	
Reason for attending FTF						
Not due to cost of screening			0.71**	0.56-0.90	0.71**	0.56-0.90
Due to cost of screening			ref.		ref.	
Patient navigation participant						
No			0.52***	0.39-0.70	0.53***	0.39-0.71
Yes			ref.		ref.	
% county residents living in poverty						
1 st tertile, <14.2					ref.	
2 nd tertile, 14.2-<19.5					1.07	0.62-1.86
3 rd tertile, 19.5+					1.36	0.80-2.32
<u>Error variance (estimate, standard error)</u>						
Region	0.05 (0.10)		0.02 (0.06)		0.01 (0.05)	
Region (county)	0.71*** (0.19)		0.52** (0.15)		0.53** (0.16)	
Level 1	0.97*** (0.03)		0.97*** (0.03)		0.97*** (0.03)	
<u>Model fit</u>						
-2 log-likelihood	10430.70		10464.43		10472.35	

* $P < .05$, ** $P < .01$, *** $P < .001$

Table 5.7

Papanicolaou (Pap) screening models for Friend to Friend + Patient Navigation follow-up respondents aged 21-64 reporting a barrier to screening (N=2,959), 3/1/12-11/5/16.

<u>Fixed effects</u>	<u>Model 1</u>		<u>Model 2</u>		<u>Model 3</u>	
	<u>Odds Ratio</u>	<u>95% CI</u>	<u>Odds Ratio</u>	<u>95% CI</u>	<u>Odds Ratio</u>	<u>95% CI</u>
Age						
40-64 years	ref.		ref.		ref.	
65+ years	1.17	0.97-1.40	1.13	0.94-1.36	1.13	0.94-1.36
Race/ethnicity/language						
African American	0.61	0.35-1.04	0.62	0.36-1.07	0.63	0.36-1.09
English Speaking Latina	0.76	0.54-1.07	0.71	0.50-1.01	0.73	0.51-1.03
Spanish Speaking Latina	1.11	0.82-1.50	0.99	0.73-1.35	1.02	0.74-1.39
Non-Hispanic White	ref.		ref.		ref.	
Education level						
Did not complete high school	1.28*	1.01-1.62	1.17	0.92-1.49	1.17	0.92-1.49
High school graduate or GED	1.28*	1.02-1.61	1.17	0.92-1.48	1.17	0.93-1.48
Some college or more	ref.		ref.		ref.	
Reason for attending FTF						
Not due to cost of screening			0.57***	0.46-0.70	0.57***	0.46-0.70
Due to cost of screening			ref.		ref.	
Patient navigation participant						
No			0.72*	0.53-0.97	0.70*	0.52-0.95
Yes			ref.		ref.	
% county residents living in poverty						
1 st tertile, <14.2					1.94*	1.02-3.71
2 nd tertile, 14.2-<19.5					1.26	0.70-2.27
3 rd tertile, 19.5+					ref.	
<u>Error variance</u> (estimate, standard error)						
Region	0.30 (0.32)		0.27 (0.29)		0.45 (0.44)	
Region (county)	0.82*** (0.21)		0.67*** (0.18)		0.65*** (0.18)	
Level 1	0.96*** (0.03)		0.97*** (0.02)		0.97*** (0.03)	
<u>Model fit</u>						
-2 log-likelihood	13577.19		13654.48		13666.86	

* $P < .05$, ** $P < .01$, *** $P < .001$

Table 5.8

Chi square tests comparing the proportions of Friend to Friend plus Patient Navigation participants without follow-up interviews to participants with follow-up interviews reporting barriers to screening (n=4,743), 3/1/12-11/5/16.

Variable	No follow-up (n, %)	Follow-up (n, %)	P
Total	1,451	3,292	
Age			
21-39 years	271, 19.7	929, 28.5	<.0001
40-64 years	657, 47.9	2,030, 62.4	
65+ years	445, 32.4	296, 9.1	
Race/ethnicity/language (%)			
African American	101, 7.2	133, 4.0	<.0001
English Speaking Latina	100, 7.2	450, 13.7	
Spanish Speaking Latina	252, 18.0	1,826, 55.5	
Non-Hispanic White	945, 67.6	882, 26.8	
Education level (%)			
Did not complete high school	168, 12.0	1,264, 38.4	<.0001
High school graduate or GED	370, 26.5	911, 27.7	
Some college or more	858, 61.5	1,116, 33.9	
Region			
North	492, 33.9	736, 22.4	<.0001
East	543, 37.4	447, 13.6	
West	236, 16.3	422, 12.8	
South	180, 9.7	1,686, 90.4	
Attended FTF due to cost of screening	194, 13.4	1,939, 58.9	<.0001
Did not attend FTF due to cost of screening	1,257, 86.6	1,352, 41.1	
% county residents living in poverty			
1 st tertile, <14.2	363, 25.0	635, 19.3	<.0001
2 nd tertile, 14.2-<19.5	461, 31.8	649, 19.7	
3 rd tertile, 19.5+	627, 43.2	2,007, 61.0	

Paper 3: The Impact of Educational Attainment on Breast and Cervical Cancer Screening Outcomes Among Rural and Border Texas Women Participating in a Patient Navigation

Intervention

Introduction

While racial and ethnic categories provide an essential framework for analyzing variation in health outcomes among a population, measures of socioeconomic status (SES) contribute to more nuanced understanding of health disparities both between and within racial and ethnic groups.¹⁷⁹ More specifically, education has provided the strongest evidence of direct and indirect effects on mortality in relation to several diseases, including cancer, after controlling for other SES measures such as occupation and income.¹⁸⁰ Analyses of educational attainment in relation to breast and cervical cancer screening substantiate the relationship between education and adherent screening behavior^{181,182} with further evidence pointing to those attaining the highest education levels benefitting the most from preventative screening.¹⁸³

Higher educational attainment, however, does not invariably translate into better health outcomes as other research describes “diminishing returns” whereby socially disadvantaged groups benefit from more education but still maintain poorer outcomes compared to their socially advantaged counterparts.¹⁸⁴ For example, more education gives increasingly better health returns such as higher rates of cancer screening, but these findings are highest for Non-Hispanic whites (NHW) and diminish to lower rates of return for other groups, such as African Americans (AA), despite higher educational attainment maintaining some benefit for both groups. A nationally representative study of breast and cervical cancer screening supports this hypothesis finding evidence of an SES gradient increasing with screening rates while NHW women experienced more pronounced increases in screening rates due to higher SES indicators,

including education, than African American (AA) or Latina women.¹⁸⁵ In another study of breast cancer screening, researchers identified women of Mexican origin as exhibiting diminishing returns compared not only to NHW women, but also to other Latinas.¹⁸⁶ Therefore, disparities in screening adherence and subsequent breast and cervical cancer-related mortality appear to be highly sensitive to educational attainment, race/ethnicity, and country of origin.

Patient navigation (PN) offers an intervention model originating from breast cancer disparities research that focuses on connecting un-/underserved communities to appropriate care within a fragmented health care system by addressing psychosocial barriers faced by women across the cancer continuum.¹³ Studies have demonstrated PN's efficacy for increasing preventative screening uptake;^{14,15} however, PN has been defined broadly with questions about measuring its impact on health outcomes.^{16,17,113} Though studies have found that rural women screen for breast and cervical cancer at lower rates³ and suffer from later stage breast cancer diagnoses⁴ and higher breast and cervical cancer mortality rates⁵ compared to urban residents, few studies have assessed interventions aiming to increase screening among these residents.

Intervention

Friend to Friend plus Patient Navigation (FTF+PN) was established in 2012 through a grant from the Cancer Prevention Research Institute of Texas (CPRIT) to expand an existing cancer education intervention operated by Texas A & M AgriLife Extension Service that sought to inform lower income, un-/underinsured women residing in approximately 70 rural and border counties across Texas aged 40+ who may be disabled, self-employed, and/or have limited English proficiency (LEP) about the need for timely breast and cervical cancer screening. The grant provided funding for clinical services and the addition of four trained, lay patient navigators to compliment a team of five regional cancer specialists tasked with follow-up for

program participants and navigating their barriers to screening, such as transportation. The intervention aimed to increase breast and cervical cancer screening rates according to American Cancer Society (ACS) guidelines for breast and cervical cancer that recommended annual mammograms for women aged 40-54 and biannual mammograms for those aged 55+ with average risk of breast cancer¹⁵⁴ and Papanicolaou (Pap) tests every 3 years for women aged 21-29 and every 5 years for women aged 30-64 with no additional screenings needed for women aged 65+ based on previously normal results.¹⁵⁵

Women attending the education intervention provided the main source of PN participants; however, other outreach activities conducted by the program staff identified women in need of PN who may not have been able to attend the initial FTF portion of the intervention. Fig. 6.1 illustrates the various data collection points and participant recruitment for the study. FTF participants completed a help request prompting PN staff to follow-up and complete an intake form when appropriate. Also, women who had contacted program staff independently or women contacted by the staff due to a referral or request outside of the FTF event could also receive PN services. Both groups received a follow-up survey approximately 6 weeks later to determine the results of the screenings; however, women not attending FTF lack the initial pre- and post-test data.

Consequently, this analysis examines PN participants exclusively in order to evaluate the programmatic goal of reaching lower educated, women of color living in rural and border counties who are at risk of delayed screening. Statistical models include interaction effects of racial/ethnic/language categories with educational attainment in logistic regressions to determine the odds of screening outcomes to test if the diminishing returns hypothesis persists in this intervention.

Methods

Data and measures

This study analyzes program evaluation data collected from PN participants from March 1, 2012 to November 5, 2016. Participants had either sought PN services after attending a FTF event (FTF+PN) or were connected to PN services independently (PN only), and their follow-up responses were recorded in separate datasets. The PN only database began with 2,884 unique participant follow-up surveys recorded during the study time frame. Women who identified their race/ethnicity as American Indian or Native American (n=4), Asian, Asian-American, or Pacific Islander (n=20), multiple racial/ethnic categories (n=23), and other race/ethnicity or missing (n=15) were excluded due to small sample sizes. Additionally, Latina participants who spoke a language other than English or Spanish at home (n=1) or did not indicate a language preference (n=41) were excluded to create exclusive categories for English Speaking Latina (ESL) and Spanish Speaking Latina (SSL) women. Finally, women who had participated in the intervention more than once (n=267) were also excluded for a total of 2,513 PN only participants.

The FTF+PN dataset for the same time frame began with 7,450 unique survey responses from intervention participants. Women who chose not to receive PN (n=2,380) and who had not received follow-up interviews (n=1,451) were excluded from the analysis. Small numbers of women identifying as American Indian or Native American (n=20), Asian, Asian-American, or Pacific Islander (n=29), multiple racial/ethnic/other categories (n=79) were once again excluded from the analysis. Latina women who spoke a language other than English or Spanish at home (n=5) and those missing this response (n=57) were also excluded. Next, women who repeated the intervention were removed (n=516) for a total of 2,913 FTF+PN participants. Finally, the

datasets were combined, and participants omitting age (n=81) and education level (n=223) were excluded for a final analytic sample of 5,122 PN participants.

Mammogram and Pap screening status determined from follow-up interviews serve as the outcome measures for the analysis. AA, NHW, and Latina women stratified by primary language use at home comprise the principle demographic variable. This variable categorizes women who exclusively identify as one of the racial/ethnic categories as well as differentiating Latinas who are English or Spanish speakers. Language use is an indication of acculturation that has been used as the primary indicator of variation in acculturation studies and provides greater insights into the differences among Latina women in this sample.¹⁵⁶ Age is determined from their year of birth, and education attainment is categorized by three levels: did not complete high school, high school graduate, or some college or more. The Institutional Review Board (IRB) of The University of Texas at Austin reviewed and approved (FWA # 00002030) the proposed study prior to analysis.

Statistical Analysis

Logistic regressions tested main and interaction effects of age, race/ethnicity, and education attainment on breast and cervical cancer screening outcomes for PN participants (N=5,122). Separate models included women aged 40+ (N=3,721) for mammogram screening outcomes and aged 21-64 (N=4,879) for Pap screening outcomes as indicated by ACS guidelines at the time of the intervention. First, demographic variables including age, race/ethnicity, and education attainment provided a baseline model. Next, interaction terms multiplying race/ethnicity/language categories and education levels are added to the models. Finally, significant interactions are further examined by stratifying education level according to each race/ethnicity/language category to examine the impact of higher educational attainment within

each group. Analyses were conducted using SAS software, version 9.4 (SAS Institute, Cary, NC).

Results

Women aged 40 to 64 comprised the largest share of the sample for each racial/ethnic group as noted in Table 5.9. The sample distribution by education level reveals college educated AA, ESL, and NHW women represented the largest portion of PN participants while women with less than a high school education had the highest participation among SSL women. As shown in Fig. 5.2, lower educated AA women also experienced the highest mammogram screening prevalence rate in contrast to college educated NHW women who experienced the highest prevalence rates for their respective racial/ethnic category. In general, Pap screening prevalence rates were lower overall than mammogram prevalence rates, with AA and NHW women having the lowest rates overall and with high school educated SSL women achieving the highest screening prevalence rate at approximately 60%.

Table 5.10 reports the odds of mammogram screening among the sample of women aged 40 and above and Pap screening for women aged 21-64. The first model only found significantly lower odds of mammogram screening among older and ESL women, while SSL women experienced higher odds of screening compared to NHW women (OR=1.27, CI=1.06-1.53). In the Pap screening model results, age was also significant with younger women experiencing higher odds of receiving a Pap test than older women. In addition, ESL (OR=2.24, CI=1.78-2.81) and SSL (OR=3.31, CI=2.82-3.90) women both had increased odds of screening for cervical cancer compared to NHW women.

The second column for mammogram and Pap screening includes the interaction between race/ethnicity/language and education level. For mammogram screening, the interaction model revealed that college educated AA women experienced lower odds of screening compared to lower educated AA women. Similarly, high school educated ESL women (OR=0.41, CI=0.20-0.86) and college educated SSL women (OR=0.47, CI=0.29-0.76) had lower odds of screening compared to their lower educated counterparts. The Pap screening outcomes demonstrated significantly higher odds of screening for high school educated SSL women compared to SSL women with less than a high school education (OR=1.55, CI=1.02-2.35); however, none of the other interaction terms were significant.

Logistic regression models stratified by race/ethnicity/language categories examined the findings from interaction models. In Table 5.11, age was a significant variable among each group screening for breast cancer except for ESL women (although it was in the same direction), and there was no significant difference in screening outcomes for AA, ESL, and SSL women based on education level. Meanwhile, the stratification revealed that both high school (OR=1.53, CI=1.05-2.23) and college educated NHW women (OR=1.58, CI=1.10-2.25) experienced more than 1.5 greater odds of screening for breast cancer compared to NHW women with less than a high school education. In Table 5.12, Pap screening results found lower odds among older AA, SSL and NHW (ESL were in the same direction but not significant) women and higher odds of screening for high school educated SSL women (OR:1.31, CI:1.09-1.58) compared to their counterparts.

Discussion

Studying the interaction between race/ethnicity and education attainment yielded valuable insights into breast and cervical cancer screening behavior among this sample of PN

participants in rural and border Texas; however, the findings did not support the diminishing returns hypothesis for either screening in this intervention. The results demonstrated a progressive benefit based on education for NHW women screening for breast cancer, but all other groups failed to show the same pattern. For Pap screening, education appeared not to factor into outcomes beyond one exception for high school educated SSL women. Still, comparisons by race/ethnicity/language categories demonstrate the intervention's focus on reaching Latina women, who have the highest incidence rates of cervical cancer in the U.S. and Texas.¹ Furthermore, the findings reflect ACS guidelines highlighting the need for early screening among younger women compared to mammogram screening. Overall, the Pap screening prevalence rates were much lower than the rates for mammogram screening. Possible explanations for this variation may be related to perceived need for the exam, cost, and availability of services although these factors were not measured in the study.

Rather than interpreting these findings as not exhibiting diminishing returns, the results most likely reflect the intervention's focus on lower educated women of color rather than the hypothesis' origin in observational data of broader populations.¹⁸⁴ Consequently, interpreting the results more broadly demonstrate that PN effectively mitigates lower educational attainment as a barrier to screening for most of the sample. Thus, lower educated women in general did not screen differently than their higher educated counterparts, although higher findings for lower educated women would have more clearly substantiated this finding.

Qualitative findings from participant interviews also demonstrate how PN overcomes educational and other SES barriers that delay screening. One example recounts a group of women who all had less than a fifth grade education and struggled with recording and understanding the details of their screening appointments. The PN was able to identify and

respond to their scheduling difficulties and assist them with their screenings. Multiple participants described how PNs helped them to access insurance coverage following a cancer diagnosis using various programs. PNs connected these women to resources that they may have been previously unaware of while revealing an enduring relationship beyond screening that follows the continuing needs of participants. Finally, many women also described the PN support related to the bureaucratic procedures that impeded their screening and treatment progress. Many lower educated women found the paperwork to be overwhelming apart from connecting with providers spanning long distances from their homes. Working with PN aided many to navigate these situations.

This study demonstrates that PN can disrupt established patterns of screening uptake among lower educated women, indicating some improvement in screening rates for lower educated women; however, PN faces distinct funding challenges as these services are not normally reimbursable expenses despite some cancer care organizations including PN as a standard part of clinical practice.^{20,175} Additionally, cancer care professionals who are charged with addressing psychosocial barriers to care, such as social workers, face workforce challenges to cover current gaps in service much less the expected growth in demand for these services.^{178,187} As a consequence, PN should be seen a system of care spanning health care and community professionals and lay individuals sharing a common goal of reducing health disparities by improving screening and treatment outcomes for individuals and groups.¹¹³ As professionals mandated to address the psychosocial barriers faced by patients, social work must play a key role in educating the current and future health care workforce to respond to the complex demands of treating both the physical and contextual factors across the cancer continuum.^{80,82}

Limitations

The interpretation of the results of this study are limited in several ways. First, the program intentionally sought un-/underserved women of color participants due to the risk for late stage diagnosis and higher cancer-related mortality; thus, it relies on a convenience sample. Program implementation varied by region to account for local differences in the population and available resources. While this approach favored adaptation based on participants' needs, the lack of consistent protocols limited the results. Follow-up interviews had not been completed for all intervention participants at the time of the analysis leading to possible bias in the results (see Table 5.13). Follow-up procedures varied from region to region with different roles for patient navigators and cancer prevention specialists leading to differences in follow-up screening rates. For example, the additional patient navigator in the South region increased their capacity to perform follow-up interviews at higher rates than the other regions. Also, participants from year 1 had a much longer timeframe to receive follow-up compared to participants in subsequent years. Furthermore, variation in participant recruitment led to many women participating in the PN intervention but not the FTF portion. While this encouraged screening among women who could not or would not attend the education intervention, participants did not complete pre- and posttest surveys during the events that would have contributed greater insights to the results.

Finally, all responses were based on self-report with possible recall bias. Also, both SES and acculturation were measured using a single item based on educational attainment and language use at home. Additional items surveying income, wealth, and occupation would strengthen the validity of the SES findings, while more comprehensive measures of acculturation would refine the interpretation of screening behavior among Latina women.

Conclusion

Educational attainment plays an important role in cancer screening outcomes that affects health outcomes differently among racial/ethnic groups. The results from this study further research into cancer screening behavior among women of varying education levels by racial/ethnic/language groups. Mammogram screening appeared to be the most sensitive to educational attainment; however, it failed to support the diminishing returns hypothesis as greater educational attainment was not associated with screening prevalence for most groups. Still, the intervention reached key groups of women vulnerable to poorer outcomes including Latinas screening for cervical cancer. Future studies with more comprehensive measures of socioeconomic status may provide greater insight into the screening behavior of disadvantaged women in rural and border Texas.

Table 5.9

Sample distribution by demographic characteristics among patient navigation follow-up respondents (N=5,122), 3/1/12-11/5/16.

	African American (n=475)	English Speaking Latina (n=449)	Spanish Speaking Latina (n=2,754)	Non-Hispanic White (n=1,444)
Age (years)				
21-39	26.8	34.8	28.3	20.8
40-64	69.8	60.5	68.5	74.5
65+	3.4	4.7	3.2	4.7
Education level				
< high school	12.8	21.2	63.8	14.3
High school	37.7	35.9	23.8	34.3
Some college+	49.5	43.0	12.5	51.4

Table 5.10

Odds of mammogram screening among patient navigation follow-up respondents aged 40+ (N=3,721) and Papanicolaou (Pap) screening among respondents aged 21-64 (N=4,879), 3/1/12-11/5/16.

	<u>Mammogram Screening (N=3,721)</u>		<u>Pap Screening (N=4,879)</u>	
Age				
21-39	-	-	ref.	ref.
40-64	ref.	ref.	0.72 (0.63-0.82)***	0.72 (0.63-0.82)***
65+	0.41 (0.31-0.55)***	0.40 (0.30-0.54)***	-	-
Race/ethnicity/language				
African American	1.21 (0.93-1.57)	2.67 (1.27-5.61)**	1.19 (0.94-1.51)	1.46 (0.78-2.71)
English Speaking Latina	0.66 (0.51-0.86)**	1.16 (0.66-2.07)	2.24 (1.78-2.81)***	2.28 (1.35-3.83)**
Spanish Speaking Latina	1.27 (1.06-1.53)*	1.87 (1.34-2.61)***	3.31 (2.82-3.90)***	2.82 (2.04-3.90)***
Non-Hispanic White	ref.	ref.	ref.	ref.
Education level				
< high school	ref.	ref.	ref.	ref.
High school	1.02 (0.85-1.23)	1.51 (1.03-2.20)*	1.09 (0.94-1.27)	0.84 (0.58-1.22)
College+	0.99 (0.81-1.21)	1.56 (1.09-2.23)*	0.95 (0.80-1.12)	0.87 (0.61-1.24)
Race/ethnicity/language X education level				
AA X <high school		ref.		ref.
AA X high school		0.43 (0.18-1.00)		0.76 (0.36-1.59)
AA X college+		0.37 (0.16-0.86)*		0.83 (0.41-1.67)
ESL X <high school		ref.		ref.
ESL X high school		0.41 (0.20-0.86)*		1.04 (0.54-1.98)
ESL X college+		0.58 (0.29-1.16)		0.93 (0.50-1.73)
SSL X <high school		ref.		ref.
SSL X high school		0.71 (0.45-1.11)		1.55 (1.02-2.35)*
SSL X college+		0.47 (0.29-0.76)*		1.00 (0.65-1.53)

* $P < .05$, ** $P < .01$, *** $P < .001$

Table 5.11

Odds of mammogram screening among patient navigation follow-up respondents aged 40+ stratified by race/ethnicity, 3/1/12-11/5/16.

	<u>African American</u> (n=342) <u>OR (95% CI)</u>	<u>English Speaking Latina</u> (n=291) <u>OR (95% CI)</u>	<u>Spanish Speaking Latina</u> (n=1,956) <u>OR (95% CI)</u>	<u>Non-Hispanic White</u> (n=1,132) <u>OR (95% CI)</u>
Age				
40-64	ref.	ref.	ref.	ref.
65+	0.30 (0.11-0.83)*	0.80 (0.33-1.97)	0.44 (0.28-0.67)***	0.31 (0.19-0.52)***
Education level				
< high school	ref.	ref.	ref.	ref.
High school	0.64 (0.30-1.38)	0.66 (0.35-1.23)	1.06 (0.83-1.36)	1.53 (1.05-2.23)*
College+	0.57 (0.27-1.22)	0.91 (0.50-1.65)	0.73 (0.54-1.00)	1.58 (1.10-2.25)*

* $P < .05$, ** $P < .01$, *** $P < .001$

Table 5.12

Odds of Pap screening among patient navigation follow-up respondents aged 21-64 stratified by race/ethnicity, 3/1/12-11/5/16.

	<u>African American</u> (n=451) <u>OR (95% CI)</u>	<u>English Speaking Latina</u> (n=425) <u>OR (95% CI)</u>	<u>Spanish Speaking Latina</u> (n=2,640) <u>OR (95% CI)</u>	<u>Non-Hispanic White</u> (n=1,363) <u>OR (95% CI)</u>
Age				
40-64	ref.	ref.	ref.	ref.
65+	0.60 (0.38-0.93)*	0.86 (0.58-1.28)	0.77 (0.65-0.92)**	0.58 (0.44-0.77)***
Education level				
< high school	ref.	ref.	ref.	ref.
High school	0.63 (0.33-1.19)	0.89 (0.53-1.50)	1.31 (1.09-1.58)*	0.84 (0.57-1.22)
College+	0.70 (0.38-1.30)	0.83 (0.50-1.38)	0.88 (0.69-1.12)	0.87 (0.61-1.24)

* $P < .05$, ** $P < .01$, *** $P < .001$

Table 5.13

Chi square tests comparing the proportions of Friend to Friend plus Patient Navigation participants without follow-up interviews to participants with follow-up interviews (n=7,450), 3/1/12-11/5/16.

Variable	No follow-up (n, %)	Follow-up (n, %)	<i>P</i>
Total	1,451	5,999	
Age			
21-39 years	19.7	23.8	<.0001
40-64 years	47.9	61.1	
65+ years	32.4	15.1	
Race/ethnicity/language (%)			
African American	7.2	4.8	<.0001
English Speaking Latina	7.2	13.8	
Spanish Speaking Latina	18.0	48.3	
Non-Hispanic White	67.6	33.2	
Education level (%)			
Did not complete high school	12.0	33.1	<.0001
High school graduate or GED	26.5	27.0	
Some college or more	61.5	39.9	

Data Collection Flow Chart

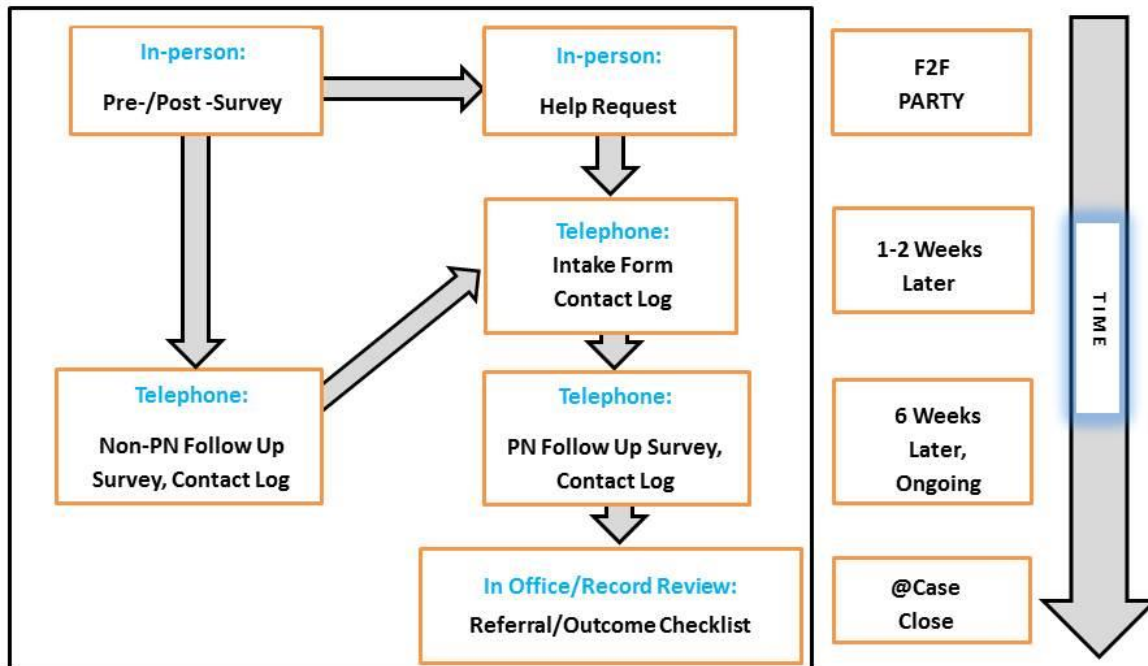


Fig. 5.1. Flowchart of Friend-to-Friend Plus Patient Navigation data collection.

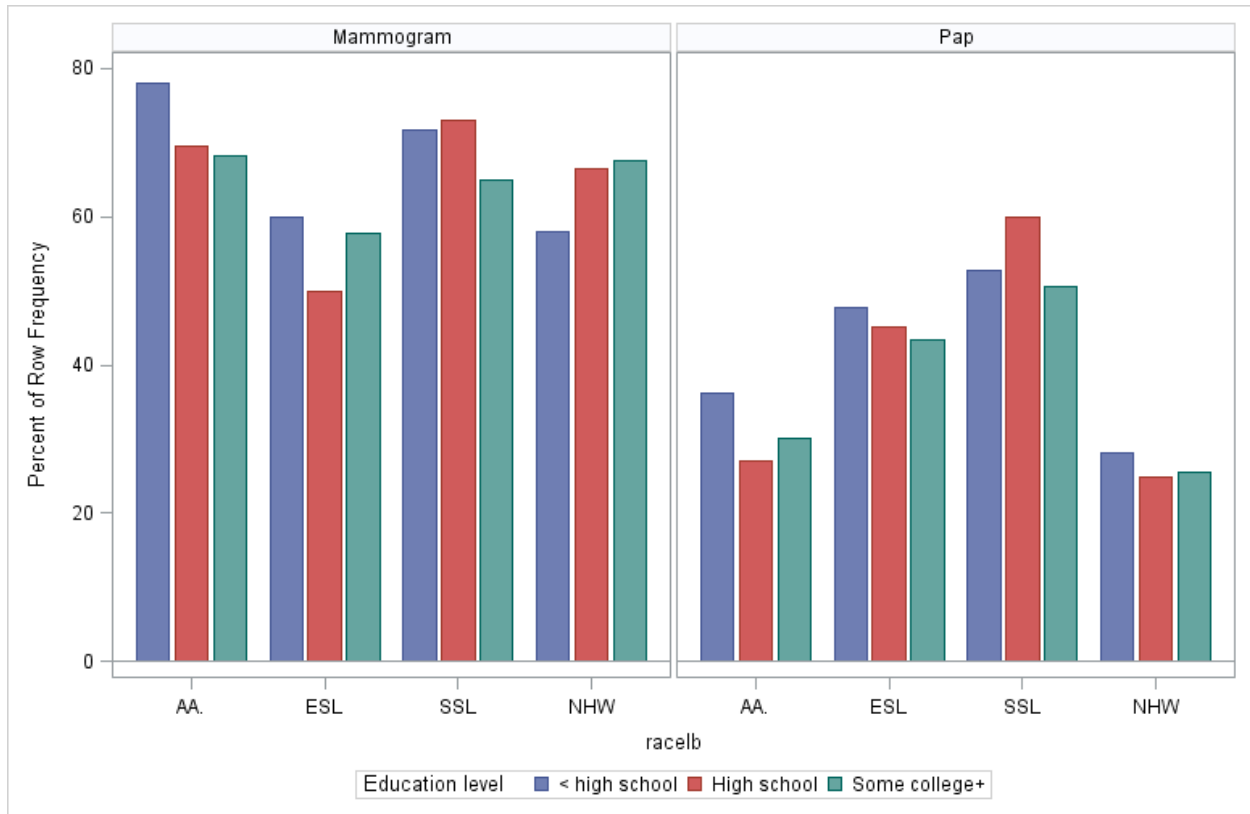


Fig. 5.2. Mammogram and Papanicolaou (Pap) screening prevalence rates by race/ethnicity/language and education level among patient navigation follow-up respondents, 3/1/12-11/5/16.

Conclusion

The analyses presented in this dissertation seek to contribute insights into breast and cervical cancer prevention behavior among rural and border residents of Texas by evaluating program participation and screening outcomes. In doing so, this project fills an important gap in knowledge regarding the implementation of PN among rural populations. FTF+PN represents a successful adaptation of PN to rural and border areas that incorporate traditional breast and cervical cancer screening services with the needs of these communities. PN practice remained flexible to respond to the varying social contexts of the women in this study demonstrating the need to culturally and linguistically tailor interventions that speak to women's needs while assessing their environmental context.

The findings from the literature review reveal that despite our understanding of the disadvantage that rural women face, very few studies draw from rural samples of women to understand how their experiences may vary from urban residents and report successful interventions specifically aimed at improving outcomes for this population. In part, this focus may lie with the source of the studies often located in urban areas with easier access to study participants and service providers. Still, the social context as evidenced by policies either supporting or detracting from prevention efforts is essential to contrast with studies that may have a more favorable policy environment. The ACA expansion is a clear example where access to preventative screening with Medicaid access for low income individuals depends greatly on your place of residence. Consequently, programs such as FTF+PN play a vital role in providing access to cancer care services by assisting with financial barriers to care. Its broad sampling of women also highlights the variation in rural communities across the state.

Summary of Findings

The formal analysis of the evaluation data began with Paper 1. This analysis demonstrated the success of PN to increase both mammogram and Pap screening among intervention participants. Lower educated women of color had higher odds of screening as the intervention sought to increase screening specifically among these women who experience disparate morbidity and mortality outcomes compared to higher educated, NHW women. Therefore, the intervention not only increases screening rates in general, it can be adapted to reach specific women and attempt to address population health disparities for un-/underserved women especially those concerned about financial barriers.

The next study further contextualized screening behavior in geographic context and its subsequent social implications. The sample consisted of women with self-reported barriers to screening. Overwhelmingly, women in the South region screened more than any other region for both exams. For mammograms, county-level poverty corresponded to higher odds of screening demonstrating once again that the intervention responded to contextual and individual needs and adapted accordingly screening where the demand was highest for services. Analyses for both screenings found lower odds for ESL women indicating that future interventions should consider these women distinctly when seeking to increase screening among these women. Once again, screening rates were higher for women with barriers if they attended the intervention due to concerns for cost and participated in PN.

Finally, the third paper examined how education attainment affected screening outcomes within racial/ethnic categories. Although NHW women saw a mammogram screening advantage based on education level, the findings for the other women were inconclusive. The models found higher odds of mammogram screening for SSL women and higher odds for Pap screening

for ESL and SSL women; however, education appeared to play little to no role in screening outcomes among PN participants.

Implications and Future Directions

The Commission on Cancer (CoC) guidelines for high-quality cancer care require accredited institutions to provide psychosocial services including patient navigation, psychosocial distress screening, and survivorship care plans, yet striving to achieve this goal for all patients faces multiple implementation challenges.²⁰ The current distribution of cancer care services favors urban areas as rural communities often lack institutions capable of meeting CoC standards leaving patients at a disadvantage of receiving comparable care.¹⁸⁸ Meanwhile, a growing number of rural hospital closures have led to decreased health care services in general particularly among socioeconomically disadvantaged and racially/ethnically diverse communities.¹⁷⁶ Moreover, cultural and financial barriers, inadequate public transport, and inaccessibility of broadband internet services compounded with scarce services and professionals negatively impact health care access for rural residents.¹⁸⁹ Consequently, implementing psychosocial services by CoC standards requires consideration of environmental factors that act as barriers to practice and participation by residents in remote areas.

Geographic evaluation of cancer-related health outcomes further substantiate the impact of the contextual factors on individual health and the relationship with provider resources. For example, spatial analyses confirm communities of color and areas of low socioeconomic status (SES) in Texas experience higher late-stage diagnosis and poorer mortality rates compared to their counterparts for breast cancer.¹⁹⁰ Similarly, area SES deprivation in Texas has been associated with higher cancer-related mortality rates for non-Hispanic whites and African Americans and surprisingly lower for Hispanics, though areas with more uninsured Hispanic

residents and physician shortages experience delayed detection of breast, lung, colorectal, and female genital cancers.¹⁷⁰ These examples further illustrate how environmental considerations in cancer care distinguish disadvantaged population groups with reduced access to cancer care services impacting health outcomes.

CoC standards reflect oncology social work's commitment to improving psychosocial outcomes for underserved patients by integrating whole-person care in their environment with cancer treatment.¹⁷⁷ Still, maintaining standards of cancer care faces challenges due to growing shortages in cancer care professionals, rising treatment costs, and higher incidence rates of cancers among an expanding and aging population.¹⁷⁸ Projections of social workers among these professionals confirm these issues. Estimates indicate that Texas will have a shortage of over 33,000 social workers by 2030, ranking it among the states with largest shortfalls of social workers in the country.¹⁸⁷ At the same time, the Bureau of Labor Statistics¹⁹¹ expects health care social workers specifically to drive the largest share of growth in employment with approximately 191,000 positions expected nationally by 2024. Although national analyses provide needed comparison among states, they fail to capture intra- or interstate spatial variation that may indicate areas of greater need due to professional shortages and area characteristics where professionals are found.

Insurance status for the adult population represents yet another barrier to care present in Texas, which has some of the highest rates of adults aged 18-64 uninsured in the nation.¹⁶³ On average, over a fourth of the population of adults does not have insurance. Thus, the widespread uninsured population prohibits access to health care leaving social workers with fewer resources to address psychosocial needs for disadvantaged individuals.

Technological innovations in psychosocial service delivery may offer the possibility to mitigate geographic isolation using telehealth and mHealth applications.⁸⁸ Telehealth interventions vary greatly, but involve the dissemination of health-related services via telecommunication technology such as smartphones (mHealth) to monitor and care for individuals remotely. Systematic reviews describe multiple service delivery approaches using mHealth applications to educate and support individuals across the cancer continuum; however, the authors note the need for further consolidation and refinement of this research to improve its evidence base.^{192,193} Despite the limitations of current research, technology-based interventions promise an innovative approach to reach isolated populations and the ability to tailor their interfaces for varying population groups based on language and culture. Consequently, service providers may be able to leverage these advances to provide better quality care to un-/underserved groups.

Improving psychosocial service delivery including cancer screening services also relies on greater collaboration among health care professionals shaping health social work education. As health care responds to complex issues in population health, multidisciplinary education foment innovation in social work practice methods reflecting real-world settings and collaborative health care professional teams.⁷³ Given social work's practice orientation addressing a range of psychosocial factors contributing to health and wellbeing, social work is well positioned to lead and facilitate interprofessional education in health care.⁸² These lessons continue as leadership in oncology social work respond with continuing education initiatives for practitioners addressing multidisciplinary collaboration while maintaining social work values of person-centered, culturally-sensitive, and evidence-informed practice.⁸⁰ Community engagement and practice are cornerstones of social work positioning the field to intervene in communities

drawing from established practice methods as well as new approaches to comprehensive health care delivery. Multidisciplinary education establishes a paradigm to analyze service care delivery from multiple perspectives that may lead to future innovation to reach un-/underserved individuals.

Future research should also examine individual SES factors beyond educational attainment with regards to cancer screening and subsequent care. Wealth, for example, has been associated with both within and between group variation in health outcomes research.^{179,194} These findings suggest future approaches to assessing SES indicators in cancer-related outcomes research that have been explored to a lesser degree compared to educational attainment. While these factors may converge (e.g., low wage workers with lower educational attainment and low wealth), each element may impact outcomes differently among population subgroups and would contribute significant gap in extant literature on this topic.

A key element missing from this dissertation is a qualitative analysis. Findings such as those outlined in the literature review could yield important insights not captured in the survey data. The evaluation included qualitative data collection; however, the practical implications of appropriately sampling and collecting qualitative data were not feasible within the scope of this project. Still, future inquiries should incorporate qualitative inquiry to strengthen the quantitative findings presented in the analyses and uncover any topics not addressed in the surveys.

To conclude, rural and border residents in Texas face multifaceted barriers to cancer screening and care that can be mitigated, in part, through evidence-informed interventions such as PN. FTF+PN has supplied further evidence that programs adapted to their environmental context can successfully reach un-/underserved individuals in need of screening services with the

goal of reducing late stage detection of breast and cervical cancer among participants. By adapting the program to reach women at the greatest risk for disparate outcomes, FTF+PN aims to foment greater health equity for disadvantaged groups of women and serve as a model for future health-related interventions bridging the gaps between the health care system and the community.

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